

Effect of Self Learning Package on Mothers of Children with Cerebral Palsy

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Abstract: The birth of a child with cerebral palsy (CP) is a potentially traumatic event for the parents and siblings so; those children need care and attention from community and pediatric care providers. *The study aimed to assess, plan, implement and evaluate the effect of self-learning package on mothers' knowledge and practices. Setting:* This study conducted at Neurology outpatient clinic of Zagazig University Hospital. *Sample:* The study subject consists of 50 mothers having children with CP were attending the previously mentioned setting at the time of this study. *Methods:* Mothers' assessment sheet, it consisted of four parts, part I: Socio demographic data of the studied subjects, part II: Past history and family history of CP, causes and complications, part III: This part concerned with assessment of child dependency in activities of daily life (ADLs), as well as mothers' awareness regarding their children needs, and part IV: Mothers' knowledge about CP and practical application of the self-learning package regarding CP, *Results:* The main results revealed that there were highly statistically significant differences between pre, post and follow up phases of self-learning package implementation, *Conclusion:* The present study findings revealed that mothers had poor knowledge and practices related to CP and its management. Subsequently, they didn't follow the correct instructions related to treatment and care. There was a positive effect of self-learning package on improving knowledge and practices of the studied mothers. *Recommendations:* Encourage use of self-learning package for mothers having children with cerebral palsy. Supply those families with counseling, self-learning package, programs, community based centers and rehabilitation centers to support them and making their life to be normal as possible.

Keywords: Cerebral Palsy (CP), Self-Learning Package, Mothers, Children, Nursing.

1. INTRODUCTION

Cerebral palsy (CP) constitutes a major health problem throughout child's life. The birth of a child who has CP is a potentially traumatic event for the family, parents, especially mothers and siblings. So, those children need attention, care and support from community and pediatric care providers (Bullough *et al.*, 2014). It is the most common permanent physical disability of childhood (Whally and Wong, 2015). A decrease in some forms of cerebral palsy have been noticed due to the treatment and prevention of Rh-factor baby and improved obstetric care that is paralleled with the development of prematurity as a cause of cerebral palsy (Bairg *et al.*, 2015).

The incidence of cerebral palsy is from 1.5 to 2 cases per 1000 live births all over the world; there are almost 300.000 affected children in United States (Neff and Weiss, 2014). Several studies have been conducted trying to reach to an estimation of the magnitude of the problem of disability in Egypt. Because of lack of agreement and standardization of definitions and procedures variable estimates were reached. The estimated prevalence varies between 11.8% and 5.6%. It is generally accepted that 5-10% of the populations have significant disabilities; CP is one of them that need rehabilitation interventions (WHO, 2016).

The term cerebral palsy means brain paralysis. It is a non-progressive disorder of movement and posture, often associated with epilepsy, mental retardation, speech, vision and hearing abnormalities according to the defect lesion of the developing brain (*Murphy and Such-Neibar, 2013*)

It is non-progressive and may be accompanied by perceptual problems, language difficulties and intellectual involvement. The etiology, clinical features and course are variable and characterized by abnormal muscle tone and coordination as the primary disturbance (*Whally and Wong, 2015*).

Cerebral palsy can be classified according to limbs involvement into monoplegic, hemiplegic, paraplegic, triplegic and quadriplegic CP, and can be classified according to physiology to spasticity, ataxia, hypotonia, tremors and mixed. Its neuroanatomical classification is pyramidal, extrapyramidal and cerebellar (*Madkour, 2017*).

The causes of CP may be prenatal such as infection with germs measles and Rh incompatibility; metabolic disorders as diabetes mellitus and hereditary cause which is a rare cause. Perinatal causes of CP are birth injuries, ventose delivery, trauma and prolonged labor. In addition, postnatal causes of CP are brain infection in the form of meningitis, lead poisoning, brain clots, drowning and falling (*Wong et al., 2010*).

The earliest manifestation of CP in the neonate who has suffered serious brain injury includes hypotonia, absent grasp, weak Moro reflexes and seizure. Delayed motor milestone in children with CP either fine or gross motor skills. The delay may range from weakness to more obvious impairments or complete immobility (*Hockenberry and Wilson, 2007*).

Cerebral palsy has many associated problems as cognitive impairments (any degree of mental retardation), seizure occurs in 70 % of CP children, speech impairment, sensory defects. Hip dislocation, scoliosis & contractures, pulmonary, feeding and eating, bowel, urinary and dental problems may also occur (*Rogers, 2012*).

Therapeutic management aimed to establish locomotions, communications and self-help; gain optimum appearance and integration of motor functions; correct associated defects and provide educational opportunities and adaptation on the needs and capabilities of the individual child (*Hockenberry and Wilson, 2007*). Parental awareness of cerebral palsy being a life-long disorder would also empower them to seek advice about their children's needs. However, the educational intervention and early intervention therapy given by a team of specialized therapists is the recommended treatment of cerebral palsy, that cerebral palsy can be prevented from occurring in the next child if the mother takes regular antenatal care and delivers in a good hospital.

Cerebral palsy child's management is best accomplished by a nurse using a multidisciplinary health care team (community based approach). The overall goal of multidisciplinary team should to provide maximum quality of care while assisting the patient in obtaining his optimal level of wellness through mapping out a long-term program of development for those children (*Maloney et al., 2014*).

Moreover the caregivers in the form of mothers play an important role in the educational process of their children, they can help in develop and carry out of educational goals and objectives. Because, mothers knows the child well to carry their role effectively so, mothers must see themselves as an equal partners with professionals in planning and implementation programming for the child. They should be aware and confident in their roles so as to make sure that the program plan is appropriate and effective to obtain holistic care (*Sherill and Bernie, 2015*).

One of the most important aspects in the rehabilitation of a child with cerebral palsy is to ensure the active co-operation and participation of the parents (*Singhi, 2014*). Researchers believe that once parents are empowered with this core knowledge about cerebral palsy right from the time of its diagnosis in their child, they would not only accept the diagnosis but also begin early intervention therapy without further delay and continue with it for an adequate time period. Cerebral palsy is a long term condition; parents will have questions and issues to resolve throughout their lives (*Rosenbaum, 2013*).

Mothers of children with CP had reported a lower quality of life, difficulties in managing the child's care and higher levels of anxiety and maladaptive behavior. In addition to, other psychological stressors which leads to disruption of family life. These in turn can have a detrimental effect on the child's personal development, care and medical treatment. Sufficient support for mothers may prevent or ameliorate these problems and indirectly achieve better outcomes for mothers and their children (*Tong et al., 2016*). Therefore, implementing a self-learning package for those families or mothers is helpful

in acquisition knowledge and practices regarding the disease and relief their stressors. Also, it is an essential step to assist families and their children to cope effectively with the disease and its management and reach adulthood safely and live a normal life as possible.

Significance of the Study:

In Egypt, there is no accurate estimation for cerebral palsy but according to *UNICEF, 2015*, CP cases in Egypt constitute approximately 4.5 million children affected with this disorder. Cerebral palsy is a serious health problem that threatens the children and their mothers throughout their life, also it is considered one of the leading causes to child morbidity and mortality and psychological stress for caregivers. Parenting a child with CP is a hard task. It is not only creates a myriad of physical and emotional problems for the child, but also an emotional and financial burden on the family.

Aim of the Study:

First, to assess knowledge and practices of mothers' regarding care of their children with cerebral palsy, second, to plan and implement self-learning package for mothers regarding care of their children with cerebral palsy and third, to evaluate the effect of self-learning package on mothers' knowledge and practices.

Research Hypotheses:

Mothers of children with CP who will receive self-learning package will be improved and obtained high scores in their knowledge and practices regarding care of their children with CP.

2. SUBJECTS AND METHODS

The subjects & methods of this study were portrayed under the four main designs as follows:

- I. Technical design.
- II. Operational design.
- III. Administrative design.
- IV. Statistical design.

I. Technical Design:

The technical design included the following:

Research design: A quasi experimental research design with pre-post assessment was used.

Setting: The study was conducted at Neurology outpatient clinic of Zagazig University Hospitals.

Subjects:

A convenient sample of 50 mothers who have children with CP, were attending the previously mentioned setting within a period of 6 months, with their children.

Inclusion criteria of the sample selection:

Mothers, who can read and write regardless their age and children with CP regardless their age or gender with moderate degree of CP.

Tool of data collection:

Mothers' assessment sheet was designed and utilized by the researcher to collect the necessary data. It consisted of 4 parts:

First part: Socio demographic characteristics of mothers as age, sex, level of education, working and economic status. It also involved children characteristics as age, sex, birth order, number of siblings and educational level.

Second part: Characteristics of cerebral palsy as onset, duration, cause, type, signs and symptoms and associated complications and problems in various body systems.

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Third Part: Assessment of children dependency in activities of daily life (ADLs) throughout self-learning package phases. This covered activities of nutrition, mobilization, walking, clothing, bathing, elimination and communications. The responses were on a three-point Likert scale: totally dependent, partially dependent and independent. Also it includes mother's awareness about their children needs throughout self-learning package phases.

Scoring: Items were scored 0, 1 and 2 for totally dependent, partially dependent and independent respectively. For each area, the scores of the items were summed up and the total divided by the number of items, giving a mean score for the part. These scores were converted into a percent score. The score 70% and more were considered independent, 50% -70% considered partially dependent and totally dependent if less than 50%.

Fourth Part: Mothers' knowledge about CP throughout self-learning package phases as, definition, disability, self-care, fits and general health care. It also includes reported practices related to CP throughout self-learning package phases. It included practice related to mobilization, daily care and prevention of injury, nutrition, management of epileptic fits, positioning, carrying and dealing with speech problems

Scoring System:

A. Knowledge Scoring System:

The total nurses' knowledge percentages were calculated for known and not known answers. Each correct answer was given one mark and zero mark for wrong or not known one. 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 more and unsatisfactory if less than 50%.

B: Performance scoring system:

The item reported to be done correctly was scored "1" and the item not done or incorrectly done was scored "0". For each area, 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 score 70% and more were considered good, 50%-70% considered fair and poor if less than 50%.

Self-learning package:

The researcher designed and implemented a self-learning package in an Arabic language after reviewing the related literature based on assessment the actual needs of the studied sample (mothers). It covered the theoretical knowledge and practical procedures. Theoretical part includes their knowledge about: Cerebral palsy as definition, disability, self-care, fits and general health care. On the other hand, the practical part included practices regarding: Mobilization, daily care, prevent injuries, nutrition, epileptic fits, positioning, speech problems and carrying. In addition, problems that the child with CP exposed to and how the mothers can deal with and solve it.

II. Operational Design:

Preparatory phase:

Review of the current and past available literature and theoretical knowledge will be done, using books, articles and magazines to develop the tools for data collection

Development of tools:

The mothers' assessment sheet was developing after extensive review of the literature. Validity: It was established for tool content by a panel of three expertise who reviewed the tools for clarity, relevance, comprehensiveness, understanding, applicability and easy for implementation. According to experts opinion some modifications were applied.

Pilot study:

After development of the tool, a pilot study was conducted on 10 % of the sample before data collection. The purpose of pilot study was to ascertain the feasibility of the tool and to detect any problems peculiar to the statement as sequence and clarity. It also helped to estimate the time needed to complete the assessment sheet. After conducting the pilot study, it was found that the sentences of the tool were clear and relevant, few words had been modified. Following this pilot study, the tool reconstructed and be ready for use.

Field work:

The actual field work was carried out over 6 months started from May 2016 to October 2016. Each mother involved in the study interviewed individually and the researcher explained the purpose of the study, the component of tools and how to answer the questions. Including data collection regarding pretest, implementation of self-learning package, post and follow up test.

The researcher was available two days per week from 8 a.m. to 2 p.m. The researcher started by introducing herself to the mothers and their children with CP and giving them a brief idea about the aim of the study, its components and the expected outcomes.

Before implementation of self-learning package, the researcher collected data related to socio demographic characteristics of the mothers as age, sex, level of education, working status and economic status and children characteristics as age, sex, birth order, number of siblings and educational level. Also characteristics of cerebral palsy as onset, duration, causes, types, symptoms and signs and associated complications and problems in various body systems. Additionally, assessment of child dependency in activities of daily life (ADLs). This covered activities of nutrition, mobilization, walking, clothing, bathing, elimination, and communications.

The responses were on a three-point Likert scale: Totally dependent, partially dependent and independent and mother's awareness about their children needs throughout self-learning package phases. Mothers' knowledge about CP throughout self-learning package phases as, definition, disability, self-care, fits, and general health care. It also includes reported practices related to CP throughout self-learning package phases. It included practices related to mobilization, daily care and prevention of injury, nutrition, management of epileptic fits, positioning, dealing with speech problems and carrying.

The researcher assessed caregiver's knowledge, practice and attitude regarding care of their children with CP before implementing self-learning package using pretest tools.

Self-learning package was distributed by the researcher to each mother clarified the purpose of the study, the researcher explained to the mothers how to use the package throughout setting directions including; the caregiver should answer the questions proceeded each chapter then read each chapter carefully and can return to the researcher to clarify what is vague or difficult to understand, the mothers shouldn't move to the next chapter unless understand and digest the content of the current chapter well, after that the mothers answer the questions which follow each chapter and should achieve the desired score, the mothers can review the model key answer of each chapter.

After finishing the implementation of self-learning package, the researcher applied posttest to evaluate mothers' knowledge and practices also follow- up test was applied after 2 months of posttest.

III. Administrative Design:

An official permission was obtained through an issued letter from the Dean of Faculty of Nursing, El-Fayoum University to director of Neurology outpatient clinics of Zagazig University Hospitals to conduct the study.

Ethical considerations:

The purpose of the study was explained to the mothers and an oral consent to participate in the study was obtained. The agreement for participation of the subjects was taken after aim of the study has explained to them; they were given an opportunity to refuse to participate. They were assured about confidentiality of data collected, which were used for the purpose of the study only. They were informed that they have the right to withdraw from the study at any time without giving any reason.

Limitations of the study:

The tools of data collection needed long time to be filled and applied in the field work and this was exhausted to the researcher and mothers. Some mothers didn't follow instructions and guidelines of care and treatment of their children and didn't attend follow up test.

IV. Statistical Design:

Data entry and statistical analysis were done using SPSS, (Statistical Package for Social Sciences), statistical soft-ware package version 20. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables and means and standard deviations for quantitative variables. Qualitative categorical variables were compared using chi-square (X²) test. Statistical significance was considered at P-value <0.05.

3. RESULTS
Table 1: Distribution of the studied mothers and their children according to their personal characteristics (n=50).

Mothers' Characteristics	Frequency (No.)	Percent (%)
Age		
- < 30	16	32.0
- 30 -	19	38.0
- 40 +	15	30.0
Job		
- Working	18	36.0
- Housewife	32	64.0
Family income (pound/month)		
- < 500	5	10.0
- 500 -	27	54.0
- 1000 +	18	36.0
Educational level		
- Read/ write	11	22.0
- Primary/preparatory/ secondary	17	34.0
- Diploma	14	28.0
- University	8	16.0
Children's characteristics		
Age / years		
- 1 - < 3	13	26.0
- 3 - < 6	17	34.0
- 6 +	20	40.0
Gender		
- Male	30	60.0
- Female	20	40.0
Order of birth		
- First	24	48.0
- Middle	15	30.0
- Last	11	22.0
Number of siblings		
- 1	14	28.0
- 2	25	50.0
- 3+	11	22.0
Education		
- Kinder garten	27	54.0
- Primary	13	26.0
- Preparatory/secondary	2	4.0
- None	8	16.0
If have special education		
- Yes	13	26.0
- No	37	74.0

Table 1: Showed distribution of the studied mothers according to their characteristics, approximately two fifth of the studied mothers were in the age group 30 to 40 (38.0%). Slightly less than two thirds of the mothers were housewives (64.0%); with more than half of them were having basic education and diploma degree, 34.0% and 28.0% respectively. The family income was between 500 and 1000 pounds per month for more than half of the families (54.0%).

As regards distribution of the studied children according to their characteristics. It was found that two fifth (40%) of them were six years old and 60% of them were male and 48% were ranked as the first child in the family, 26% only were following special education and had primary education.

Table 2: Medical history and disease characteristics of cerebral palsy children in the study sample (n=50).

Medical history and disease characteristics	Frequency (No)	Percent (%)
Onset (years):		
- < 2	43	86.0
- 2 - < 6	4	8.0
- 6 +	3	6.0
Duration of illness (months):		
- < 6	22	44.0
- 6 - < 12	16	32.0
- 12 - < 24	10	20.0
- 24 +	2	4.0
Time of diagnosis		
- < 1	3	6.0
- 1 - < 2	40	80.0
- 2 - < 3	5	10.0
- 3+	2	4.0
Causes of cerebral palsy in the child		
- Labor related (asphyxia, hemorrhage and head injury).	20	40.0
- Pregnancy related (bleeding, eclampsia, etc).	16	32.0
- Post labor (infection, hypoglycemia, hypothermia).	8	16.0
- Others	5	10.0
- Hereditary	1	2.0
Symptoms at onset*		
- Epilepsy	39	78.0
- Loss one of the senses	13	26.0
- Delayed movement	12	24.0
- Flaccidity	9	18.0
- Spasticity	7	14.0
- Mental retardation	3	6.0
- Others	9	18.0
Type of cerebral palsy		
- Mixed	17	34.0
- Flaccid	11	22.0
- Tremor	8	16.0
- Fits	7	14.0
- Mental retardation	5	10.0
- Compound	2	4.0
Other congenital malformations		
- Yes	24	48.0
- No	26	52.0
Presence of fits		
- Yes	37	74.0
- No	13	26.0
	N=37	
- On fits therapy	37	100.0

* Some children have more than one symptom at the onset.

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Characteristics of the child illness are presented in **table 2**, which demonstrated that the onset age was less than two years for the majority of children (86.0%), and its duration mostly less than one year and 80.0 % of them were diagnosed after the first year. The most commonly reported causes of CP were those related to child labor (40.0%), and pregnancy (32.0%). The majority reported epilepsy as the onset symptom (78.0%), while mental retardation was the least mentioned (6.0%). About one-third of the cases had mixed type of CP (34.0%). Slightly less than half of children had other congenital anomalies (48.0%), and the majority had fits (74.0%) that were treated among all of them (100.0%).

Table 3: Locomotor and neuro-behavioral problems among cerebral palsy children in the study sample (n=50).

Problems	Frequency (No.)	Percent (%)
Locomotor system (paralysis)		
- One limb	22	44.0
- Hemiplegia	12	24.0
- paraplegia	7	14.0
- Triplegia	6	12.0
- Quadriplegia	3	6.0
Posture		
- Spastic with embryo position	20	40.0
- Walk on tips of toes	13	26.0
- Crawl on one side	6	12.0
- Swing head and trunk	5	10.0
- Unable to sit	4	8.0
- Bending forward	2	4.0
Muscles		
- Relaxed	26	52.0
- Flaccid	24	48.0
Mental retardation		
- None	13	26.0
- Mild	22	44.0
- Moderate	9	18.0
- Severe	6	12.0
Special senses losses		
- None	10	20.0
- Hearing	14	28.0
- Speech	15	30.0
- Vision	5	10.0
- Touch	6	12.0
Behavioral problems		
- None	15	30.0
- Biting	13	26.0
- Sucking fingers	12	24.0
- Biting nails	10	20.0

This table demonstrated that slightly more than two fifth of children had paralysis in one limb (44.0%) and (6.0%) had quadriplegia. The most commonly reported posture was the spastic with embryo position (40.0%), while the least was bending forward posture, which affected two children (4.0%). Muscles were relaxed in slightly more than half of the children (52.0%).

Concerning the neuro-behavioral problems, this table illustrated that slightly less than three fourth of the children had mental retardation (74.0%), 44.0% of them had mild degree mental retardation. As for the special senses losses, speech problems were the most common (30.0%), followed by hearing defects (28.0%). The most frequently reported behavioral problems were biting and sucking fingers, 26.0 % and 24.0 %, respectively.

Table 4: Gastro-intestinal (GIT), respiratory, urinary and dermal problems among CP children (n=50).

Problems	Frequency (No.)	Percent (%)
<u>Mouth problems</u>		
- None	13	26.0
- Dental caries	14	28.0
- Teeth distortion	12	24.0
- Teeth erosion	6	12.0
- Abnormal position of mandibles	5	10.0
<u>Gum problems</u>		
- None	17	34.0
- Edematous	11	22.0
- Inflamed	10	20.0
- Ulceration	7	14.0
- Bleeding	5	10.0
<u>Tongue problems</u>		
- None	16	32.0
- Rosy	13	26.0
- white spots	8	16.0
- injuries	7	14.0
- Cracked	6	12.0
<u>GIT problems</u>		
- None	10	20.0
- Mastication / deglutition	16	32.0
- Constipation	9	18.0
- Stool incontinence	9	18.0
- Esophageal regurgitation	6	12.0
<u>Food intake</u>		
- Liquid	19	38.0
- Semi-solid	21	42.0
- Solid	10	20.0
<u>Urinary problems</u>		
- None	15	30.0
- Incontinence	16	32.0
- Recurrent infections	10	20.0
- Obstruction	9	18.0
<u>Respiratory problems</u>		
- None	19	38.0
- Recurrent pneumonia	19	38.0
- Cough and choking while eating	12	24.0
<u>Skin problems*</u>		
- None	24	48.0
- Yellowish	9	38.0
- Bed sores	17	34.0
- Bluish edematous	16	32.0

* Some children have more than one skin problem.

This table describes the GIT, respiratory, urinary and dermal problems among studied children. It indicated that the majority had some types of mouth problems, dental caries was the most common (28.0%); also about two-thirds of them had gum and tongue problems. The most commonly reported GIT problems were related to mastication and deglutition as it affected about one third of the children (32.0%). As for the type of food, only one- fifth of the children were able to take solid food (20.0%), while more than two-fifth were taking semi-solid food (42.0%).

As regards other systems this table shows that, more than two thirds of children had urinary problems and the most commonly reported was incontinence, which affected slightly less than one third of them (32%). As for respiratory problems, about two- fifth of them suffered from recurrent pneumonia (38%). Slightly more than half of children had skin problems, about one- third of them had bed sores (34%).

Table 5: Dependency in activities of daily life (ADLs) among cerebral palsy children as reported by mothers' throughout the self-learning package phases

Daily life activities	Phase (s)						X ² Test p-value Pre-post	X ² Test p-value pre-Follow up
	N=50							
	Pre Intervention		Post Intervention		Follow up			
	No	%	No	%	No	%		
Nutrition:								
- Dependent	38	76.0	0	0.0	0	0.0	<0.001*	<0.001*
- Partially dependent	10	20.0	32	64.0	2	4.0		
- Independent	2	4.0	18	36.0	48	96.0		
Mobilization:								
- Dependent	40	80.0	0	0.0	0	0.0	<0.001*	<0.001*
- Partially dependent	9	18.0	28	56.0	1	2.0		
- Independent	1	2.0	22	44.0	49	98.0		
Walking:								
- Dependent	38	76.0	0	0.0	0	0.0	<0.001*	<0.001*
- Partially dependent	11	22.0	28	56.0	1	2.0		
- Independent	1	2.0	22	44.0	49	98.0		
Clothing:								
- Dependent	36	72.0	0	0.0	0	0.0	<0.001*	<0.001*
- Partially dependent	13	26.0	30	60.0	1	2.0		
- Independent	1	2.0	20	40.0	49	98.0		
Bathing:								
- Dependent	37	74.0	0	0.0	0	0.0	<0.001*	<0.001*
- Partially dependent	11	22.0	34	68.0	2	4.0		
- Independent	2	4.0	16	32.0	48	96.0		
Elimination:								
- Dependent	38	76.0	0	0.0	0	0.0	<0.001*	<0.001*
- Partially dependent	11	22.0	31	62.0	1	2.0		
- Independent	1	2.0	19	38.0	49	98.0		
Communication:								
- Dependent	33	66.0	0	0.0	0	0.0	<0.001*	<0.001*
- Partially dependent	11	22.0	26	52.0	1	2.0		
- Independent	6	12.0	24	48.0	49	98.0		
Total activities:								
- Dependent	8	16.0	0	0.0	0	0.0	<0.001*	<0.001*
- Partially dependent	42	84.0	21	42.0	0	0.0		
- Independent	0	0.0	29	58.0	50	100.0		

The effect of the implementation of the package on children's dependency in ADLs is described in this table. At the pre-implementation phase, the majority of children were dependent in elimination (76.0%) and 72.0% in clothing. After implementation of the package, statistically significant improvements were noticed both at post and follow-up phases (p<0.001). Where at the post phase, none of them was fully dependent and most of them were partially dependent and at the follow-up, the majority of children were independent in their ADLs.

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Table 6a: Needs of cerebral palsy's children as reported by mothers throughout the self-learning package phases.

Children' needs	Phase (s)						X ² Test p-value Pre-post	X ² Test p-value pre-Fu
	N=50							
	Pre Intervention		Post Intervention		Follow up			
	No	%	No	%	No	%		
Physiotherapy:								
- Agree	20	40.0	0	0.0	0	0.0		
- Uncertain	22	44.0	1	2.0	1	2.0		
- Disagree	8	16.0	49	98.0	49	98.0	<0.001*	< 0.001*
Personal equipment:								
- Agree	23	46.0	0	0.0	0	0.0		
- Uncertain	21	42.0	1	2.0	2	4.0		
- Disagree	6	12.0	149	98.0	146	96.0	<0.001*	< 0.001*
Elimination training								
- Agree	26	52.0	0	0.0	0	0.0		
- Uncertain	18	36.0	1	2.0	1	2.0		
- Disagree	6	12.0	49	98.0	49	98.0	<0.001*	< 0.001*
Side rails in child's bed:								
- Agree	23	46.0	0	0.0	0	0.0		
- Uncertain	20	40.0	0	0.0	1	2.0		
- Disagree	7	14.0	50	100.0	49	98.0	<0.001*	< 0.001*
Oral hygiene:								
- Agree	24	48.0	0	0.0	0	0.0		
- Uncertain	22	44.0	0	0.0	1	2.0		
- Disagree	4	8.0	50	100.0	49	98.0	<0.001*	< 0.001*
Stretching muscles:								
- Agree	25	50.0	0	0.0	0	0.0		
- Uncertain	20	40.0	1	2.0	2	4.0		
- Disagree	5	10.0	49	98.0	48	96.0	<0.001*	< 0.001*
Joint wide range:								
- Agree	28	56.0	0	0.0	0	0.0		
- Uncertain	17	34.0	0	0.0	2	4.0		
- Disagree	5	10.0	50	100.0	48	96.0	<0.001*	< 0.001*
Head cover:								
- Agree	28	56.0	1	2.0	0	0.0		
- Uncertain	18	36.0	1	2.0	2	4.0		
- Disagree	4	8.0	48	96.0	48	96.0	<0.001*	< 0.001*

Table 6b: Needs of cerebral palsy children as reported by mothers throughout the self-learning package phases.

Children' needs	Phase (s)						X ² Test p-value Pre-Post	X ² Test p-value Pre-Follow up
	N=50							
	Pre Intervention		Post Intervention		Follow up			
	No	%	No	%	No	%		
Dental care:								
- Agree	25	50.0	0	0.0	0	0.0		
- Uncertain	22	44.0	1	2.0	2	4.0		
- Disagree	3	6.0	49	98.0	48	96.0	<0.001*	<0.001*
Respiratory exercise:								
- Agree	27	54.0	0	0.0	0	0.0		
- Uncertain	20	40.0	1	2.0	1	2.0		
- Disagree	3	6.0	49	98.0	49	98.0	<0.001*	<0.001*

Frequently talking to the child:								
- Agree	22	44.0	0	0.0	0	0.0		
- Uncertain	23	46.0	0	0.0	1	2.0		
- Disagree	5	10.0	50	100.0	49	98.0	<0.001*	<0.001*
Use of soft cushion for fits:								
- Agree	23	46.0	0	0.0	0	0.0		
- Uncertain	21	42.0	1	2.0	1	2.0		
- Disagree	6	12.0	49	98.0	49	98.0	<0.001*	<0.001*
Avoid to stop convulsions during fits:								
- Agree	29	58.0	0	0.0	0	0.0		
- Uncertain	16	32.0	0	0.0	1	2.0		
- Disagree	6	12.0	50	100.0	49	98.0	<0.001*	<0.001*
Keep head in normal position:								
- Agree	27	54.0	0	0.0	0	0.0		
- Uncertain	19	38.0	1	2.0	0	0.0		
- Disagree	4	8.0	49	98.0	50	100.0	<0.001*	<0.001*
Avoid sudden stretch of limbs:								
- Agree	24	48.0	0	0.0	0	0.0		
- Uncertain	21	42.0	1	2.0	0	0.0		
- Disagree	5	10.0	49	98.0	50	100.0	<0.001*	<0.001*

Table 6a and b illustrated the effect of the package on mothers' awareness about the needs of their CP children. Before implementation of the package, most mothers didn't aware of the CP children' needs. This was mostly evident as regards needs related to use of joint wide range of motion, use of head cover and avoidance of stopping convulsions during fits, which were considered to be not important by more than half of them, 56.0%, and 58.0%, respectively. Also this table showed statistically significant improvements in mothers' awareness about their children' needs in post and follow up phases of the package, where the majority of the mothers considered all these needs are very important to the child ($p < 0.001$).

Table 7: Mothers' knowledge and reported practices related to CP and disability throughout self-learning package phases:

Satisfactory Knowledge about	Phase(s)						X ² Test p-value Pre-post	X ² test p-value Pre-FU
	(n=50)							
	Pre Intervention		Post Intervention		Follow up			
	No	%	No	%	No	%		
Cerebral palsy	12	24.0	45	90.0	46	92.0	< 0.001*	< 0.001*
Disability	26	52.0	48	96.0	49	98.0	< 0.001*	< 0.001*
Self- care	21	42.0	48	96.0	49	98.0	< 0.001*	< 0.001*
Epileptic fits	16	32.0	47	94.0	48	96.0	< 0.001*	< 0.001*
Health care	24	48.0	50	100.0	49	98.0	< 0.001*	< 0.001*
Adequate reported practices about								
Mobilization	12	24.0	46	92.0	43	86.0	<0.001*	<0.001*
Daily care	4	8.0	44	88.0	43	86.0	<0.001*	<0.001*
Injury prevention	7	14.0	45	90.0	43	86.0	<0.001*	<0.001*
Nutrition	6	12.0	49	98.0	48	96.0	<0.001*	<0.001*
Epileptic fits	25	50.0	49	98.0	50	100.0	<0.001*	<0.001*
Positioning	14	28.0	48	96.0	49	98.0	<0.001*	<0.001*
Speech problems	9	18.0	49	98.0	45	90.0	<0.001*	<0.001*
Carrying	12	24.0	49	98.0	48	96.0	<0.001*	<0.001*

The effect of implementation of self-learning package on mothers' knowledge and their reported practices is demonstrated in this table. It is evident that at the pre-test the percentages of mothers with satisfactory knowledge were low, with the lowest being related to CP itself (24.0%). On the other hand, slightly more than half of mothers had satisfactory knowledge about disability (52.0%). After implementation of the self-learning package, statistically significant improvements were noticed in mothers' knowledge in all tested areas ($p < 0.001$). These improvements continued to increase throughout the follow-up phase, except for the health care, which showed a very slightly decline.

This table also illustrated the effect of the package on mothers' reported practices related to CP. It can be noticed that the percentages of mothers with adequate reported practices were very low at the pre-test, with the lowest being related to daily care (8.0%), and nutrition (12.0%). Meanwhile, half of mothers had adequate practices related to epileptic fits (50.0%). After implementation of the self-learning package, statistically significant improvements were noticed in mothers' practices in all areas ($p < 0.001$). These improvements showed slight declines at the follow-up phase, except for the areas of epileptic fits and positioning, which continued to increase.

4. DISCUSSION

Mothers of children with CP, play a central and essential role in providing home care, they become nurses, pharmacists and physician for their children (*Abd EL-Aziz et al., 2013*). So, self-learning package implemented for those mothers in order to supply them with the needed knowledge and practices to decrease family stressors and achieve better outcome for children and assist them to develop adaptive behavior and increase self-care. Therefore, this study was conducted to evaluate the effectiveness of self-learning package on mothers of children with CP.

The main concern of this study was to assess mothers' tasks, needs, and problems and supply them with the needed information based on identified needs and problems. The study involved 50 mothers having children with CP. The results of the current study revealed that most of the studied mothers were ranked in the category of 30 to 40 years old. This result was in contrast with *Khalil (2010)*, who studied rehabilitation program for children with CP and caregivers and revealed in her study that, there is an equal distribution of the sample in the three age categories between less than 30 and more than 40. Age is important in parenting and care of child and understands newly experiences with parenting.

The present study showed that most of the studied mothers had basic education and diploma degree, were housewife and having inadequate income. In support to this *Luckmann (2009)* highlighted that when the mother is better educated, this means better job and higher income, more health awareness and ability to help throughout child's life.

As regards to children characteristics, it was found that two fifth of them were six years' old and most of them were males. This may be related to tendency of most families to nurture and managing the male child. The present study revealed that half of them were ranked as the first in birth order. In contrast, *EL-Shinnawy (2001)*, who found in her study about impact of stress of chronic illness on children & their parents at Cairo University, that the second child was the highest affected, as it constituted about two thirds of the cases in her study.

The present study demonstrated that the onset age was less than two years for the majority of children and its duration mostly less than one year. Incongruent to *Khalil, (2010)*, who found in her study that the onset age for most children was 2 years and its duration mostly less than one year. This is supported by *Karande et al. (2008)* who found in her study about impact of an educational program on parental knowledge of CP that, the majority of the parents had noticed a delay in developmental milestones and/or abnormal muscle tone in their child before the first birthday.

Cerebral palsy, except in its mildest forms, can be diagnosed in the first 12 to 18 months of life (*Eicher & Batshaw, 2013*). In the present study, it is important to note that although the majority of parents had noticed a delay in developmental milestones and / or abnormal muscle tone in their children before the first birthday, the diagnosis of cerebral palsy wasn't made in the majority of them till they were above two years of age. This indicates that the majority of children with cerebral palsy are either referred late or that parents try out all other options before bringing over the child for treatment. This is supported by *Karande et al., 2008* who found in her study that the diagnosis of CP wasn't made in almost one-third of cases till they were above two years of age.

The most commonly reported causes of cerebral palsy in this study were those related to child labor and pregnancy. This is supported by *Karande et al. (2008)* who found in her study that the causative factor for CP was birth asphyxia in most of them, neonatal meningitis in one fifth, and kernicterus in the minority.

The present study revealed that, the majority reported epilepsy as the onset symptom, while mental retardation was the least mentioned. In contrast, *Karande et al. (2008)* reported that the majority of parents had noticed firstly a delay in developmental milestones and/or abnormal muscle tone in their children.

As per the **Swedish** classification for the types of cerebral palsy diagnosed was spastic quadriplegia in 69.2%, spastic diplegia in 15.3%, spastic hemiplegia in 3.9%, athetoid in 7.7%, and hypotonic in 3.9% children (*Hagberge et al., 2008*), in the present study there are about one-third of the cases had mixed types of cerebral palsy. Slightly less than half of the children had other congenital anomalies, and the majority had fits that were treated among all of them.

According to the present study, the highest affection of locomotors system among CP children was monoplegia which affected about half of them. On the other hand, the least affection was quadriplegia. In addition, the most commonly reported posture was the spastic with embryo position, while the least was the bending forward posture. These findings were in accordance with *Megahed et al. (2015)* who similarly found that monoplegia was the highest incidence locomotor problem among CP children. Furthermore, the results related to posture abnormalities are in agreement with *Delserra et al. (2014)*.

Concerning the neuro-behavioral problems, mental retardation with different grades affected the majority of CP children. However, this is mostly mild in about one fourth of them. This finding is incongruence with *Wong et al. (2010)* who found that half of CP children had mild degree mental retardation.

As for the special senses losses, speech problems were the most common, followed by hearing defects. Furthermore, the most frequently reported behavioral problems were biting nails and sucking fingers. This result is in agreement with *Rogers (2012)* who found that more than two thirds of CP children suffer from speech problems. Also, *Gresh (2017)* reported that CP children may have hearing loss, which might be sensory neural or more commonly conductive.

The present study findings demonstrated that the majority of CP children had some types of mouth problems, with dental caries being the most common. This result may be related to improper dental hygiene. This is in agreement with *Thomas and Akobeng (2016)* who showed that the incidence of dental caries is increased among CP children.

Most of them had some gum and tongue problems and the most commonly reported gastro-intestinal problems were related to mastication and deglutition as it affected about one third of children. These results are in congruent with the findings of the study of *Stevenson and Megurk (2013)* which showed that all forms of mouth-gum-tongue-GIT problems were common among the majority of CP children, with prevalence rates reaching 80%.

Concerning the type of food they able to take, only one- fifth of the children were able to take solid foods, while more than two-fifth were taking semi-solid foods. In the line of this study, *Rogers (2012)* mentioned that the majority of children with CP take semi-liquid foods. This was attributed to the mastication and deglutition problems that affected most of CP children.

As regards other systems problems among CP children, the current study showed that more than two thirds of the children had urinary problems, in the form of incontinence and respiratory problems in the form of recurrent pneumonia. Also skin problems especially bed sores. In the line with the present study, *Stevenson and Megurk, (2013)* found that all forms of urinary, respiratory problems as well as recurrent pneumonia were most common among CP children.

On assessing mothers' knowledge about CP, disability, self-care, epileptic fits and health care before self-learning package implementation. The present study revealed low level of satisfactory knowledge in general. This may be related to low educational and socio-economic levels of mothers and indicates that educational intervention significantly helped in improving mothers' knowledge. In support to this finding *Karande et al. (2008)* found in her study lack of sufficient knowledge about core basic issues of CP. This has been highlighted by *Forburg and AbouFotouh, (2015)* who emphasized that knowledge deficit is the main cause of unawareness about nature of the disease which exposes the child to risk of complications.

After implementation of the package significant improvements were noticed in mothers' knowledge in all tested areas. These improvements continued to increase throughout the follow-up phase, except for the health care, which showed a very slight decline. This finding indicates successful use of self-learning package which based on identified needs of mothers and children.

Regarding Mothers' reported practices related to cerebral palsy and disability. The present study indicated a very low percentage of adequate mothers' practices. This was especially noticed regarding daily care and nutrition. This low level of adequate practices may be attributed to low level of knowledge and inadequate experience and lack of follow up as mentioned before. Meanwhile, the pre implementation mothers' practice related to caring for epileptic fits was highest compared to other areas. This may be attributed to fear of mothers from this attack which might pose a real risk endangering the life of the child.

After implementation of the package, significant improvements were noticed in mothers' practices in all areas. These improvements showed slight declines at the follow-up phase, except for the areas of epileptic fits and positioning, which continued to increase. This finding point to success of the self-learning package which could be explained by the suitability of its practical components and by responding of the package to mothers' needs.

The implementation of the self-learning package on CP children also involved self-care component. According to the study finding the majority of CP children were totally dependent on others in various activities of daily life (ADLs) as reported by mothers. In this respect, *Thomas and Akobeng (2016)* reported that more than two thirds of children with CP are totally dependent in activity of daily living.

This could be related to the disability they suffer from and other problems or may be attributed to over protection by mothers and their continuing attempts to help their disabled children in every activity and not allowing them to depend on themselves. This misconception was noticed during implementation of the package, which was reflected on the success of the package. Thus after implementation of the package, significant improvements was noticed in the percentage of independence of children in all ADLs both at post and follow-up phases. Similar improvements in independence of CP children in ADLs were reported by *Stevenson and Megurk, (2013)* and *Peter and Barney, (2016)* after training programs have been implemented.

Another aspect addressed in this study was mothers' awareness about the needs of their CP children. Before self-learning package implementation most mothers were not aware about many of their children' needs. This was most evident as regards dental care and respiratory exercises. This low level of awareness about these needs may be due to low educational level and lack of knowledge.

After self-learning package implementation significant improvements in mothers' awareness about various needs of CP children. This was evident both at the post and follow-up phases of the package. Awareness about these basic needs such as physiotherapy, use of personnel equipment and training in elimination is very important since achievement of these needs would help CP child to make the maximum use of the examining functions and lead to better life. *Whally and Wong (2015)* emphasized the importance of raising caregivers' awareness about their CP children' needs, which would be reflected on better care of their children.

5. CONCLUSION

The main results revealed that there were highly statistically significant differences between pre, post and follow up of self-learning package implementation; the present study findings revealed that mothers had poor knowledge and practices related to CP, its management. Subsequently, they did not follow the correct instructions related to treatment. There was a positive effect of self-learning package on improving knowledge and practices of the studied mothers.

6. RECOMMENDATIONS

Based on the current study findings, the following recommendations can be deduced:

- Encourage use of self-learning package for mothers having children with cerebral palsy.
- The need for continuous education and parental training programs for caregivers and families about CP children to supply them with needed knowledge, practices & physiotherapy.
- Develop rehabilitation programs by all hospitals, units, for caregivers and children, through a simple booklet (related to disease, treatment, diet, practices related to rehabilitation) with updated knowledge and instructions about CP.
- Provision the guidelines booklet to caregiver's to help them in improving their knowledge and practices by needed information and apply this guidelines booklet and give it to all newly admitted children in all centers, hospitals and units to increase quality of care and coping of children.

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