

Enhancing the Quality of Life for Children with Cerebral Palsy At Benha City

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Abstract

Cerebral palsy is one of a number of neurological disorders that affect body movement and muscle coordination. Nursing intervention of these children is crucial to maintaining their life and improving their quality of life. Therefore, *the aim* of this study was to enhance the quality of life for children with cerebral palsy through assess mothers' knowledge and practice regarding care of children with CP, design, implement and evaluate the constructed training program according to mothers' deficit. The research hypothesis was enhancing quality of life for children with cerebral palsy. A **sample** of 80 mothers of children with CP included in this study. The study was conducted at physiotherapy unit at Benha Hospitals. **The tools of data** collection were 1) mothers and child assessment sheet was constructed by the researcher, 2) Cerebral palsy quality of life questionnaire, developed by (*Waters et al., 2006*). **The results** showed significant improvement in mothers' knowledge and practice regarding caring for their children with CP, and also showed slightly improvement in children quality of life after program implementation. **The study concluded** that the program succeeds in improving the mothers' knowledge and practice regarding CP. After three months of implementation the program, the mothers' knowledge and practice was decline but still

higher than before the program regarding all items about knowledge and practice. **The study recommended** that teaching mothers different aspects of caring of their children having cerebral palsy to improve their quality of life updated pamphlets, posters and Arabic booklets about CP to facilitate the improvement of their knowledge.

Key Words: Cerebral palsy Quality of life

Introduction:

Cerebral palsy is a disorder affecting the central nervous system of newborns and infants. It involves damage to the cerebrum, a part of the brain largely responsible for motor function. One of the most common symptoms of cerebral palsy is spasticity, or an increase in muscle tone and contraction that interferes with movement. The affected body parts can range from a single limb to the entire body (**Mettleman, 2009**).

Cerebral palsy caused by abnormalities in parts of the brain that control muscle movements. The majority of children with cerebral palsy are born with it, although it may not be detected until months or years later. The early signs of cerebral palsy usually appear before a child reaches 3 years of age. The most common signs are a lack of muscle coordination when performing voluntary movements (ataxia); stiff or tight muscles and exaggerated cerebral palsy is a group of disorders that affect a person's ability to move and to

maintain balance and posture. The disorders appear in the first few years of life. Usually they do not get worse over time. Children with cerebral palsy may have difficulty walking. They may also have trouble with tasks such as writing or using scissors. Some have other medical conditions, including seizure disorders or mental impairment (**National Institute of Neurological Disorders & stroke, 2010**).

Quality of life is the degree of well-being felt by an individual or group of people. Unlike standard of living, quality of life is not tangible thing, and so cannot be measured directly. It consists of two components: physical and psychological. The physical aspect includes things such as health, diet, and protection against pain and disease. The psychological aspect includes stress, worry, pleasure and other positive or negative emotional states (**Costanza et al, 2008**).

Quality of life for children with cerebral palsy refers to subjective well-being focuses on the health related component of life satisfaction such as self care, mobility, and community. Assessment of quality of life reflect personal evaluation of daily experience, and resonate with other subjective outcomes, such as life satisfaction, sense of coherence and self concept **(Michael et al, 2007)**.

Education of parents and caregivers of children with cerebral palsy is a vital part of success of these children and the most parents and even caregivers do not fully understand how much can be done and how much hope there is to improve quality of life for children with cerebral palsy. In many cases, parents and caregivers don't even know where begin and how deal and care for their children **(Martin, 2006)**.

The goal of management of cerebral palsy is not to cure or to achieve normally but to increase functionality, improve capabilities, and sustain health in terms of locomotion, cognitive development, social interaction, and independence. The best clinical outcomes result from early, intensive management. Optimal treatment in

children requires a team approach **(Taylor, 2005)**. A modern team approach focuses on total patient development, not just on improvement of a single symptom. Treatment programs encompass physical and behavioral therapy, pharmacologic and surgical treatments, mechanical aids, and management of associated medical conditions. In physical, occupational, speech, and behavioral therapies, the goals include enhancing patient and caregivers interactions while providing family support **(Kriger, 2006)**.

Rehabilitation management of children with cerebral palsy (CP) brings together parents and nurses. The primary goal of the contact is to improve the individual child's potential and improve the child's functional outcomes. Frequently, parents are interested in not just their own child, but the population of children with cerebral palsy. Physicians can provide information for both purposes. Successful parent–professional relationships are rewarding and powerful. Combining the passion of the parent and the expertise of the physician can enhance collaboration for advocacy efforts that improve outcomes for children with cerebral palsy (A

Foundation of Hope for Children with Cerebral Palsy, 2009).

Meeting the daily needs of a family member with cerebral palsy can be very hard. If the child has cerebral palsy, he will seek family and community support. Help to join a support group to talk with other parents who have a child with special needs so mothers don't feel alone. Also may find counseling useful, and help mothers understand and deal with the wide range of emotions that mothers may feel when their children had cerebral palsy. The child will need help too. Providing emotional support for the child can help him or her to deal with cerebral palsy (Golonka, 2008).

Incidence of cerebral palsy:

In the industrialized world, the incidence of cerebral palsy is about 2 per 1000 live births (Thames Valley Children's Centre, 2007). In the United States, approximately 10,000 infants and babies are diagnosed with CP each year, and 1200–1500 are diagnosed at preschool age (United Cerebral Palsy Research and Education Foundation, 2007). The incidence of cerebral palsy in developed countries is approximately 2- 2.5/1000 live births (Singapore, 2008).

International prevalence of cerebral palsy is approximately 1.5-2 cases per 1000 live births. The incidence of cerebral palsy has not changed in more than 4 decades, despite significant advances in the medical care of neonates (Thorogood, 2009). Extrapolation of incidence rate for cerebral palsy in Egypt is 2,234/total population (US Census Bureau, Population Estimates, 2010).

The aim of the study was to enhance the quality of life for children with cerebral palsy through:-

- Assess mothers' knowledge and practice regarding care of children with cerebral palsy.
- Design, implement and evaluate the constructed training program according to mothers' deficit and child condition.

Research hypotheses:

A training educational program for mothers about care of children with cerebral palsy will enhance their quality of life.

Subjects and Method

The present study was conducted with the aim of enhancing quality of life for children with cerebral palsy, this will be achieved through designing, implementing and evaluating the

educational program to mothers.

Study Design

Interventional study

Setting;

The study was carried out in Benha University Hospitals, Benha Educational Hospitals, and Children Specialized Hospitals at Benha City.

Sample

A convenience sample of consists of 80 mothers having children with cerebral palsy.

Criteria of inclusion

- Mothers have a child with cerebral palsy.
- Both sex of children.
- Age of children, from 4 to 12 years.

Ethical and legal considerations:

- The necessary official permissions for data collection and implementation of the educational program was obtained by submission of official letters issued from the Dean of the Faculty of Nursing, Benha university to the administrators of the hospitals in Benha city.
- The aim of the study was explained to each subject before applying the tools to gain their confidence and trust.

-An oral consent was obtained from each subject to participate in the program.

-The tools of this study weren't touching the subject's shyness.

-The study was conducted in safe places for the mothers.

-Data was collected and treated confidentially.

C-Tools of Data collection

Two tools were used for collecting data

1- Interviewing questionnaire

Questionnaire sheet was constructed by the researcher, after reviewing related literature and under supervision of the supervisor that covered the following.

Part I:

- Socio-demographic data of mothers' age, level of education, occupation, number of children in family, and health problem....., etc.

- Child's age, sex and birth order.

Part II:

- Assessment of the mothers' knowledge of regarding cerebral palsy (Definition, causes, signs & symptoms, complication...,etc).

Assessment of mother's practice about care of cerebral palsy (feeding,

dressing, bathing, toileting...etc).

Assessment of the daily living activities of the child.

2-Cerebral palsy quality of life questionnaire for children (CPQOL- child), developed by international multidisciplinary team of clinical and child health researcher, with collaboration of he parents and children with cerebral palsy (**Waters et al., 2006**).

Questionnaire for children with cerebral palsy aged 4 to 12 year it includes:

- Parent- proxy version (for parents of children aged 4 to 12 years comprising 66 items.
- The CP QOL-Child measures the quality of life of children with cerebral palsy. It assesses several aspects of a child's life including physical wellbeing, social wellbeing, emotional wellbeing, school, access to services, and acceptance by others. This form of the Instrument was developed for assessing children aged 4-12 years.
- Most items have the following item stem: 'How do you think your child feels about...' These items have a 9 point rating scale, where 1=very

unhappy, 3=unhappy, 5=neither happy nor unhappy, 7=happy and 9=very happy. The few items where this stem and rating scale is not appropriate, such as items concerning pain, are worded differently. For example: 'How does your child feel about the amount of pain that they have?' The rating scale for item of this kind is, 1=not upset at all, to 9=very upset, and 'How much pain does your child have? ' The rating scale for item of this kind is, 1= No pain at all, to 9= A lot of pain, and also 'How much discomfort does your child experience? ' The rating scale for item of this kind is, 1= No discomfort at all, to 9= A lot of discomfort. And 'Is your child concerned about having cerebral palsy? ' The rating scale for item of this kind is, 1= Not all concerned, to 9= Very concerned, and 'Is your child bothered by hospital visits? ' The rating scale for item of this kind is, 1= No at all bothered to 9= Very bothered, and 'Does your child worry about who will take care of them in the future? ' The rating scale for item of this kind is, 1= Never, 2=Rare,

3=Sometimes, 4= Often, to 5= Always

Scoring of variables:-

Scoring the CP QOL- Child

Scoring involves two steps:

1. Items are transformed to a scale with a possible range of 0-100. The scores for every time range from 1-9, except for item 'Does your child worry about who will take care of them in the future? ' The scores for every time range from 1-5, for this item the following formula must be used:

If person scored 1, recode to 0

If person scored 2, recode to 25

If person scored 3, recode to 50

If person scored 4, recode to 75

If person scored 5, recode to 100

Scoring system of knowledge and practice . All knowledge variables were weighted according to the items included in each question. A question that implies a 5 items answer have a score of 5 and another that implies 4 items answer have a score of 4 and so on and each item has answer with unknown that implies 0.

- The mothers' total score was classified as the following

- Satisfactory > 50%

- Unsatisfactory < 50%

Field of work;

A-Pilot study

A pilot study was carried out on 10% of the sample for the purpose of modification and clarification. Participants in the pilot study were not included in the sample. And there was no modification of the designed questionnaire.

B- Operational Design

1-First Phase;

This phase included assessment of the knowledge and practice of the mothers about cerebral palsy through using the developed tools as a pre-test

2-Second phase;

This phase Included analysis of the pretest findings and identification of mothers' knowledge and practice toward cerebral palsy issues then cerebral palsy educational program was designed.

A Guide booklet:-

The booklet was designed by the researcher using simple Arabic languages and different illustrated pictures in order to facilitate subjects understanding.

3-Third Phase ;(Planning &Implementation);

Based on the results from the interviewing questionnaire and the

quality of life questionnaire as well as literature review, and educational program regarding the cerebral palsy issues were developed by the researcher.

- Implementation of educational program which entails 5 sessions.
- The time of each session will be verified 60 minutes, different teaching strategies e.g. (Lectures, and group discussion) will be used.
- The sessions were conducted at physiotherapy unit of the previous hospitals.
- Program implemented through a period of 10 month, taking into consideration the time allotted the treatment visits which subjects receiving guidance and instructions.
- Mother's knowledge and Practice will be evaluated by the end of the sessions as a post- test.

General Objectives

By the end of the cerebral palsy educational program, mothers of children with cerebral palsy will be able to have adequate and proper knowledge and practice toward cerebral palsy and care for their children.

Specific Objectives:-

By the end of the program, the mothers will be able to:

- define concept of cerebral palsy.
- Identify causes of cerebral palsy.
- Identify symptoms of cerebral palsy.
- Identify complications of cerebral palsy.
- Identify treatment of cerebral palsy.
- List needs of child having cerebral palsy.
- Identify care of cerebral palsy child.

*General and specific objectives of the educational program will be designed after

4-Fourth Phase;

Follow up test will be conducted after 3 months using the same post-test tool.

III:- Administrative Design

An official approval was obtained to conduct the study. The title and objectives of the study were illustrated as well as the main data item to be covered, and the study was carried out after gaining the necessary approval.

IV- Statistical Design:

The collected data were organized, categorized, tabulated and analyzed using electronic computer. Data was presented in the table by using Mean, Standard deviation, number and percentage and other statistical tests such paired t-test correlation coefficient was calculated between socio-

demographic data and total knowledge score and between total knowledge score.

Results:

Table (1) showed that about 65% of Children were hospitalized after birth. Regarding child's problems after birth 75% of them have hypoxia. And also 63.75% were having jaundice and 67.5% were having convulsion. Regarding to difficult in swallowing about 67% of them has difficult in swallowing. And about 67.5% do not speak, while 25% of them speak but with difficulty. And 72.5% having hearing problems. Regarding the movement of the Children about 30% of them can't do any movement, while 17.5% walk alone hardly. Also about 75% of them having dental problems.

Table (2) revealed that about 62% of mothers reported that problems facing them due to child disability were economical over load, followed by difficult transportations about 12%, while reported about 10% of them that had no enough rehabilitation service, 7% of them reported un acceptance by society, and finally about 7% reported family psychological problems.

Table (3) shows that there were highly

significant improvement in knowledge mean scores of mothers regarding to cerebral palsy items during immediate post test and Three months after test as compared to pre program mean scores P (<0.001).

Table (4) shows that there was highly significant improvement in practice mean scores of mothers about caring for children with cerebral palsy during immediate post test and after three months test as compared to pre program mean scores p (<0.001).

Table (5) shows that there were significant improvement in quality of life of children with cerebral palsy mean scores of mothers regarding to social wellbeing and acceptance during immediate post test and after three months test as compared to preprogram mean scores p (<0.05). Except in items - Get along with adults. The highest mean score was related to be accepted by family, followed by get along with their brothers and sisters.

Table (6) shows that there were highly significant improvement in quality of life of for children with cerebral palsy mean scores of mothers regarding Physical wellbeing & Functioning domain, during immediate post test and

after three months test as compared to pre program mean scores $p (<0.001)$. Except in items, -Communication with people they don't know well, and - Ability to keep up academically with their peers. The highest mean score was related to -communication with people they know well followed by -The way they use their arms and hands.

Table (7) shows that there were significant improvement in quality of life for children with cerebral palsy mean scores of mothers regarding Participation & physical health domain, during immediate post test and after three months test as compared to pre program mean scores $p (<0.05)$. Except in items -Ability to participate in social events outside of preschool or school, - Ability to participate in their community, -Physical health, and -The way they use their legs, that mean score was $p (<0.001)$.

Table (8) shows that there were no significant improvement in quality of life for children with cerebral palsy mean scores of mothers regarding Emotional& self esteem domain, during immediate post test and after three months test as compared to pre program mean scores $p (>0.05)$. Except in items -

Get along with mother that there were highly significant improvement during immediate post test and after three months test as compared to pre program mean scores $p (<0.001)$.

Table (9) shows that there were significant improvement in quality of life for children with cerebral palsy mean scores of mothers regarding Pain and impact of disability dimension, during immediate post test and after three months test as compared to pre program mean scores $p (<0.05)$, except in items -Child concerned about having cerebral palsy, and -mothers' happy, during immediate post test and after three months test as compared to pre program mean scores.

Table (10) showed that there was positive highly statically significant correlation between mothers' education, and total knowledge & total practice. Also there was a positive significant correlation between mothers, occupation and total knowledge & total practice. While there was no significance correlation between mothers' age and total knowledge & total practice.

Table (11) showed that there was no positive significance correlation

between total knowledge and total practice before, while immediately post, but after three months there were positive highly significant correlation.

Table (12) showed that there was Positive statically significant

correlation between total quality of life and mother's education. And there was no significance correlation between total quality of life and mother's age, and occupation.

Table (1) : Percentage distribution of children according to their general health status and problems.

Items	Number =(80)	%
<u>Child hospitalized after birth</u>		
- Yes	52	65
- No	28	35
<u>Child's problems after birth</u>		
- Hypoxia	60	75
- Preterm	16	20
- Low birth weight	2	2.5
- Trauma	2	2.5
<u>History of jaundice</u>		
-yes	51	63.75
-No	29	36.25
<u>History of convulsion</u>		
-yes	54	67.5
-No	26	32.5
<u>Child talking</u>		
-Yes	6	7.5
-No	54	67.5
- Speak with difficulty	20	25
<u>Child hearing</u>		
-yes	22	27.5
-No	58	72.5
<u>Awareness of the child to mother</u>		
-yes	58	72.5
-No	22	27.5
<u>Difficult in swallowing</u>		
-yes	54	67.5
-No	8	10

- Simple difficult	18	22.5
<u>Bladder Control</u>		
-yes	15	18.75
-No	65	81.25
<u>Dental problems</u>		
-yes	60	75
-No	20	25
<u>Appearance of congenital anomalies</u>		
-yes	3	3.75
-No	77	77.25
<u>movement ability</u>		
-Sit with support	3	3.75
<u>-Sit alone</u>	24	30
<u>- Stand with support</u>	11	13.75
<u>- Walk with support</u>	4	5
<u>Walk alone hardly -</u>	14	17.5
<u>Can't able to do any movement -</u>	24	30
<u>body position</u>		
<u>Hypotonia</u>	47	58.75
<u>Normal</u>	33	41.25
<u>Child irritability</u>		
<u>-yes</u>	19	23.75
<u>-No</u>	61	76.25
<u>Affected part in the body</u>		
<u>-Hemiplegia</u>	15	18.75
<u>-Diplgia</u>	21	26.25
<u>-Quadraplgia</u>	44	55

Table (2): Percentage distribution of problems facing mothers due to child disability

Items	Number =(80)	%
<u>Financial</u>		
- Economical over loud	50	62.5
- Difficult transportations	10	12.5
- No enough rehabilitation services	8	10

Social & psychological		
-Un acceptance by society & family isolation	6	7.5
-Family psychological problems	6	7.5

Table (3): Mean score of mothers' knowledge regarding Cerebral palsy before, immediately after, and after three months

Knowledge Item	Mean ±SD		t test	P Value	Mean ±SD		t test	P value
	Before	Immediately after			Before	After three months		
Cerebral palsy								
Definition	.402 ±1.200	1.900±.301	-11.65	<0.001	1.200±.402	1.862±.346	-10.35	<0.001
Causes	.191±1.037	1.750±.435	-13.99	<0.001	.191±1.037	.466±1.687	-12.11	<0.001
Clinical picture	.284 ±1.087	1.850±.359	-14.09	<0.001	.284±1.087	1.800±.402	-13.209	<0.001
Treatment	.219±1.050	1.750±.435	-13.57	<0.001	.219 ±1.050	1.737±.442	-13.183	<0.001
Complication	.157±1.025	1.737±.442	-13.99	<0.001	.157 ±1.025	1.587 ±.495	-10.078	<0.001
Child's Needs	.191±1.037	1.825±.382	-15.10	<0.001	.191±1.037	.435± 1.750	-12.90	<0.001
Total	.708± 6.437	1.056±10.812	-03.89	<0.001	.708±6.437	1.39±10.437	-21.94	<0.001

Table (4): Mean score of mothers' practice in daily activities regarding Cerebral palsy before, immediately after, and after three months.

Item	Mean ±SD		t test	P Value	Mean ±SD		t Test	P value
	Before	Immediately after			Before	After three months		
Activities of Daily Living (practice)								
Eating	428±. 1.237	1.812±.392	-10.33	<0.001	428±. 1.237	1.750± .435	-7.701	<0.001
Drinking	.392±1.187	1.850±.359	12.45-	<0.001	.392±1.187	1.775± .420	-10.09	<0.001
Dressing	.382±1.175	1.800±.402	11.47-	<0.001	.382±1.175	1.737 ± .442	-9.602	<0.001
Bathing	.346±1.137	1.787±.411	10.09-	<0.001	.346±1.137	1.725± .449	8.616-	<0.001
Teeth	.301±1.100	1.862±.346	-15.92	<0.001	.301±1.100	1.825± .382	-13.604	<0.001
Hair	.402±1.200	1.812±.392	11.17-	<0.001	.402±1.200	1.762±.423	-9.188	<0.001
Walk& run	.382±1.175	1.725±.499	-9.826	<0.001	.382±1.175	1.662±.475	-8.669	<0.001
Play	.382±1.125	1.687±.466	10.07-	<0.001	.382±1.125	1.637±.483	-8.689	<0.001
Sleep	.455±1.287	1.925±.265	-11.787	<0.001	.455±1.287	1.887±.317	-9.903	<0.001
Communication	.317±1.112	1.750±.785	-11.787	<0.001	.317±1.112	1.700±.461	10.09	<0.001
Toileting	.317±1.162	.435±1.750	-10.078	<0.001	.317±1.162	1.687±.466	-9.344	<0.001
Total practice	2.84±12.90	1.597± 19.137	-15.170	<0.001	2.84±12.90	1.597 ±19.137	-7.68	<0.001

Table (5): Mean of social wellbeing acceptance dimension of quality of life among subject before, immediately after, and after three months.

Item	Mean ±SD		t test	P value	Mean ±SD		t test	P value
	Before	Immediately after			Before	After three months		
Social wellbeing & acceptance								
1-Get along with people, generally	12.25±59.6	65.0±12.33	4.307-	<0.001	12.25±59.6	63.75±12.51	-2.973	<0.05
2-Get along with other children at preschool or school	27.85 ±16.08	21.01±31.39	2.560-	<0.05	27.85 ±16.08	20.075±30.098	-2.189	<0.05
3-Get along with other children out side preschool or school	7.55±52.50	53.44 ±8.66	-4.307	<0.05	7.55±52.50	52.187±7.11	.376	0.05>
4-Get along with adults	3.93±50.63	50.94±4.78	2.560	0.05>	3.93±50.63	50.93±4.79	1.650	0.05>
5-Get along with their teachers and/or carers	16.07 ± 27.84	17.91±28.41	-1.754	<0.001	50.63 ± 3.93	26.06±16.35	-.987	0.05>
6-Going out on trips with the family	12.44±66.88	12.2 ±67.50	-4.307	0.05>	12.44±66.88	65.31±12.25	1.686	<0.05
7-Get along with their brothers and sisters	33.95±71.39	33.1±72.31	10.463	0.05>	33.95±71.39	72.00±31.37	-.418	0.05>
8- Get along with mother	12.56±86.87	12.54±88.43	-2.295	<0.05	12.56±86.87	12.57±87.81	-1.136	0.05>
9-Accepted by their family	20.27±80.62	81.87± 19.06	-2.039	<0.05	20.27±80.62	81.65±16.27	-.686	0.05>
10-Accepted by other children at preschool or school	23.42±14.2	16.9±25.97	-1.000	<0.05	23.42±14.2	15.71±24.27	-.992	0.05>
11-Accepted by other children outside of preschool or school	.000±50.00	50.31±2.79	-1.000	0.05>	.000±50.00	50.31±2.79	-1.000	0.05>
12- Accepted by adults	47.500±8.53	.000±50.00	2.62	<0.05	47.500±8.53	49.44±5.03	1.725	0.05>
13-Accepted by people in general	50.00±9.74	6.62 ±51.9	2.53	<0.05	50.00±9.74	3.93±50.63	.630	0.05>

Table (6): Mean of Physical wellbeing & Functioning dimension of quality of life among subject before, immediately after, and after three months.

Item	Mean ±SD		t test	P value	Mean ±SD		t test	P value
	Before	Immediately After			Before	After three months		
Physical wellbeing & Functioning								
1- Ability to play on their own	17.31±58.44	15.75±60.3	-1.000	<0.05	17.31±58.44	58.75±58.75	-.276	0.05>
2-How to communication with people they know well	17.3±62.83	13.31±67.81	-3.672	<0.001	17.3±62.83	66.25±13.83	-2.25	<0.05
3-How to communication with people they don't know well	7.38±49.06	7.44±49.7	-1.423	0.05>	7.48±49.1	49.68±7.43	-1.42	0.05>
4-The way other people communicate with them	8.43 ±49.68	14.25±60.94	-8.040	<0.001	8.43±49.68	60.93±14.25	-8.040	<0.001
5- The way they sleep	11.1 ±53.44	12.7±57.2	-3.734	<0.001	11.1±53.44	55.31±13.007	-1.512	0.05 >
6-The way they use their arms	19.4 ±54.4	17.78±62.8	-6.344	<0.001	19.4±54.4	±17.76 61.56	-5.330	<0.001
7-The way they use their hands	19.4 ±54.4	18.2±62.8	-6.344	<0.001	19.4±54.4	±18.20 61.56	-5.330	<0.001
8-The way they use their legs	12.33±27.50	15.4±36.25	-5.905	<0.001	12.33±27.50	34.68±15.14	-5.062	<0.001
9-Ability to keep up academically with their peers	24.1 ±16.93	24.4±18.76	-.747	0.05>	24.1±16.93	±22.92 17.825	-.351	0.05>
10-Opportunities in life	4.77±49.06	7.27±51.56	-2.963	<0.05	4.77±49.06	50.62±5.59	-2.295	<0.05
11-Ability to dress themselves	13.65±48.13	55.0±14.56	-4.666	<0.001	13.65±48.13	±13.83 53.75	-3.818	<0.001
12-Ability to eat or drink independently	17.77±49.38	16.85±61.56	-7.602	<0.001	17.77±49.38	±16.77 60.62	-6.553	<0.001

Item	Mean ±SD		t test	P value	Mean ±SD		t test	P value
	Before	Immediately After			Before	After three months		
13-Ability to use the toilet by themselves	15.59±34.38	16.52±44.1	-6.425	<0.001	15.59±34.38	±14.98 42.81	18.849	<0.001

Table (7): Mean of Participation & physical health dimension of quality of life among subject before, immediately after, and after three months.

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Item	Mean ±SD		t test	P value	Mean ±SD		t test	P value
	Before	Immediately after			Before	After three months		
Participation & physical health								
1-Ability to play with friends?	18.44±56.25	16.68±57.81	-2.295	<0.05	18.44±56.25	±16.38 56.87	-.705	0.05>
2-Ability to participate at preschool or school	25.5±14.51	27.34±17.6	-2.433	<0.05	25.5±14.51	16.33±25.14	-2.433	<0.05
3-Ability to participate in recreational activities	16.96±57.2	16.3±58.13	-1.754	<0.05	16.96±57.2	57.81±15.70	-.532	<0.05
4-Ability to participate in sporting activities	13.31±32.2	13.25±33.75	-1.921	<0.05	13.31±32.2	32.81±12.94	-.705	0.05>
5-Ability to participate in social events outside of preschool or school	11.32±45.31	16.2±59.7	-8.138	<0.001	11.32±45.31	58.43±15.88	-7.626	<0.001
6-Ability to participate in their community	10.1±45.94	10.52±50.00	-3.915	<0.001	10.1±45.94	49.06±10.097	-3.031	<0.05
7-Physical health	12.44±45.63	14.22±51.9	-5.132	<0.001	12.44±45.63	50.93±13.45	-3.65	<0.001
8-The way they get around	5.48±48.75	8.87±50.62	-2.531	<0.05	5.48±48.75	49.37±6.86	-1.423	0.05>
9-Ability to do the things they want to do	15.9 ±31.9	15.65±34.7	-3.165	<0.05	15.9±31.9	33.12±16.77	-1.070	0.05>
10-Ability to keep up physically with their peers	14.96±34.42	13.18±37.18	-2.394	<0.05	14.96±34.42	35.93±14.80	-1.129	0.05>

Table (8) : Mean of Emotional wellbeing& self esteem dimension of quality of life among subject before, immediately after, and after three months.

Item	Mean ±SD		t test	P value	Mean ±SD		t test	P value
	Before	Immediately after			Before	After three months		
Emotional wellbeing& self esteem								
1-The way they look	8.32±46.88	6.77±51.25	-3.77	<0.001	8.32±46.88	49.68±6.28	-2.583	<0.05
2-Their life in general	7.73±48.13	8.32±53.12	-3.19	<0.001	7.73±48.13	51.56±6.08	-2.18	<0.05
3-The way they see themselves	6.77±48.75	10.77±51.56	-3.165	<0.05	6.77±48.75	50.31±9.32	-2.295	<0.05
4- The way they see their future	6.77±48.75	10.09±50.93	-2.752	<0.05	6.77±48.75	50.00±8.89	-2.039	<0.05
5-How happy is your child	.000±50.00	9.82±54.00	- 4.270	<0.001	.000±50.00	52.81±7.95	- 3.16	<0.001
6-Child's access to treatment	33.12±11.78	12.18±34.37	1.423	<0.05	33.12±11.78	11.9±33.75	.575	0.05>
7-Child's access to therapy	28.43±11.76	13.01±30.31	-1.42	0.05>	28.43±11.76	12.64±29.69	1.423	0.05>
8-Child's access to specialized medical or surgical care	36.±12.54	12.57±37.81	2.039	<0.05	36.±12.54	37.50±12.57	1.348	0.05>
9-Ability to get advice from a pediatrician	49.37±6.86	5.59±50.63	2.039	<0.05	49.37±6.86	.000±50.00	2.1518	0.05>
10-Child's access to extra help with learning at preschool or school	3.92±49.37	4.77±50.93	-1.921	<0.05	3.92±49.37	2.79±50.31	-1.348	0.05>
11-The special equipment they have at home	49.43±14.66	15.94±51.00	2.441	<0.05	49.43±14.66	15.1±51.56	2.295	<0.05
12-The special equipment they	26.50±15.14	26.74±15.75	-1.000	0.05>	26.50±15.14	15.59±25.59	.016	0.05>

Item	Mean ±SD		t test	P value	Mean ±SD		t test	P value
	Before	Immediately after			Before	After three months		
have at their school								
13-The special equipment that is available in the community	10.52±52.812	12.09±55.93	-3.359	<0.001	10.52±52.812	54.68±11.31	-1.929	<0.05
14-Access to respite care	5.5±51.25	10.29±55.31	-3.915	<0.001	5.5±51.25	53.75±8.98	-2.621	<0.05
15-The amount of respite care you receive?	6.6±51.87	9.819±54.6	-3.165	<0.05	6.6±51.87	53.43±8.66	-3.165	<0.05
16-How easy it is to get respite	5.5±51.25	8.98±53.75	-2.963	<0.05	5.5±51.25	52.50±7.547	-1.423	0.05>
17-Child's access to community services and facilities	7.95±52.81	10.705±55.937	-3.359	<0.05	7.95±52.81	54.37±9.55	-1.686	<0.05

Table (9): Mean of Pain and impact of disability dimension of quality of life among subject before, immediately after, and after three months.

Item	Mean ±SD		t test	P value	Mean ±SD		t test	P value
	Before	Immediately after			Before	After three months		
Pain and impact of disability								
1- Child bothered by hospital visits	49.53±58.75	46.11±70.00	-3.165	<0.05	49.53±58.75	65.00±47.99	-2.295	<0.05
2- Child bothered when he miss school for health reasons	28.55±10.10	24.17±6.98	1.219	0.05>	28.55±10.10	10.72±29.94	-.199	0.05>
3-Child bothered by being handled by other people	35.93±15.00	28.43±8.75	2.295	<0.05	35.93±15.00	13.75±34.65	1.000	0.05>
4-Child worries about who will take care of them in the future	15.78±6.56	13.76±5.62	1.754	<0.05	15.78±6.56	6.25±14.06	.445	<0.05
4-Child concerned about having cerebral palsy	41.16±21.25	35.93±15.00	2.295	<0.05	41.16±21.25	12.50±33.28	2.158	0.05>
6-Pain does your child have	41.17±21.25	35.93±15.00	2.295	<0.05	41.17±21.25	18.75±39.27	1.000	0.05>
7-Child feeling about the amount of pain they have	42.82±23.75	38.23±17.50	2.295	<0.05	42.82±23.75	18.75±39.27	1.270	0.05>
8-Discomfort do You experience	49.01±61.25	50.17±53.75	2.531	<0.05	49.01±61.25	50.00±50.31	3.165	<0.05
9-Mothers physical health	16.9±62.50	16.80±64.06	-2.295	<0.05	16.9±62.50	63.12±15.89	-.815	0.05>
10-Mothers work situation	11.52±45.00	8.98±46.25	-2.039	<0.05	11.52±45.00	45.31±9.81	-.376	0.05>
11- Family's financial situation	11.8±18.44	11.09±20.62	-2.752	<0.05	11.8±18.44	19.37±10.50	-1.000	0.05>
12-Mothers' happy	13.63±53.43	12.09±59.06	-4.789	<0.001	13.63±53.43	58.43±11.89	-3.667	<0.001
13-Mothers' confident that can report how child feels	30.18±90.00	19.11±96.25	-2.295	<0.05	30.18±90.00	26.50±92.50	-1.000	0.05>

Table (10): correlation between total knowledge and total practice regarding mothers' characteristics.

Variable	Total Knowledge				Total practice			
	Pre program		Post program		Pre program		Post program	
	R	p	r	P	R	p	r	P
Age	.038	0.05>	.058	0.05>	.220	0.05>	.124	0.05>
Education	.646**	<0.001	.255*	<0.001	.688*	<0.001	.319*	<0.001
Occupation	.018	0.05>	.115	0.05 <	.104	0.05>	.319*	0.05 <

Table (11): Correlation between total knowledge & total practice before, immediately post, and after three months.

Variable	Pre program		Post program		After Three Months	
	R	p	R	P	r	P
Total knowledge & Total practice	.068	0.05>	.809**	<0.001	.766**	<0.001

Table (12): Correlation between total quality of life & mother's age, education, occupation, total knowledge, and total practice.

Total quality of life	R	P
Age	.165	0.05>
Education	.243*	<0.05
Occupation	.041	0.05>

Discussion

Cerebral palsy describes a group of permanent disorders of the development of movement and posture, causing activity limitation that attributed to non progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviors, by epilepsy, and by secondary musculoskeletal problems **Anonymus, (2007).**

When a child is diagnosed with cerebral palsy, the family's lives are changed

forever. This does not mean that their lives will not be full, rich and rewarding; it simply means that they may be different to what they imagined. There may be some challenges to be overcome, yet there will also be the same exciting, happy times that all families experience. The Centre for Cerebral Palsy we aim to help parents and families meet the challenges that cerebral palsy may pose head on **The Center For Cerebral palsy,(2010) .**

To address these challenges, we developed the educational program to help children and their mothers to cope

with cerebral palsy and find way to improve their quality of life. The program includes practical and information on all aspects of living with cerebral palsy as well as educational activities tailored to meet each child and mothers needs.

Discussion of the studied sample will be presented in the following regarding types of motor defects in the studied children, table (1) it was observed that the most common motor defect is quadriplegia reported about more half of them 55%. This finding is in accordance with **Galijard, (1997), & Elsyed, (2003)**. Who found that half of cerebral palsy children had spastic quadriplegia. In the present study more than half of children have hypotonia, this is in agreement with **Ford, et al, (1996)**.who found that more than two third of children with cerebral palsy suffer from abnormal posture.

Hearing loss is a problem more than two third of cerebral palsy children 72.5% in the present study having hearing loss. This result is emphasized by **Elsyed, (2003)** and **Mahmoud, (2004)**. And disagreed with **Gersh, (1997)** and **Afifi, (2006)**, who found that a small percentage of children have

hearing loss. Meanwhile, the present study revealed that, impairments in communication especially language, which more than half of them having impairment in communication this is congruent with **Avery & First, (1997)** and **Hussien, (2002)**. Who found that expressive and receptive speech problems are common in children with cerebral palsy.

The present study revealed that more than half of children 67.5% having history of convulsion table (1). This is in agreement with **Abdel Monem, (2004), Krigger, (2006), and Ahmed, (2009)** who emphasized that one half of children with cerebral palsy demonstrate seizure activity.

Dental caries is a common health problem of cerebral children as found in this study about 75% of them having dental problems; this could be due to poor dental hygiene or mothers' ignorance about the importance of dental care for their children. **Inga et al, (2001)**. Found that more than 90% of children with cerebral palsy have oral motor dysfunction. The severity of oral dysfunction makes it difficult for some cerebral palsied children to be adequately nourished. Abnormal

neuromuscular coordination of the tongue, lips, and cheeks - which leads to poor dental alignment and periodontal problems. And the incidence of dental caries is increased among cerebral palsy children result from improper dental hygiene, congenital defects, high carbohydrate intake and retention, dietary imbalance with poor nutritional intake, inadequate fluoride, and difficulty in mouth closure and drooling.

Regarding the risk factors of cerebral palsy, table (1) the result emphasized that more than two third of mothers have natal problem which hypoxia more common problem. Preterm is consider the second risk factor about 20% of them were preterm is at congruent with **Mohamed, (2008) and Ahmed, (2009)** who mentioned that a preterm birth child is at risk for cerebral palsy, while **London et al, (2007)** reported that very premature child is also at risk for CP because of his or her immature CNS, compared with **Moustafa, (2002)** he added that around forty percent of children with CP have been prematurely born.

Head trauma is other risk factor of CP, **Hitchcock et al (2003)** reported that

only small percent of children acquire CP after birth from head trauma, this is in agreement with this study that about 2.5% percent of children have trauma, this disagree with **Ball & Bindler, (2006)** who mentioned that head trauma is consider as a major source of brain injury, and subsequent motor dysfunction.

Jaundice is reported as other risk factors of CP children **Ball & Bindler, (2006)** mentioned that hyperbilirubinemia predisposed the child to a higher risk factor of CP, and also **Price & Gwin, (2008)** who added that untreated high level of bilirubin can cause CP. In addition to **Pillitteri, (2007)** who mentioned that neonatal hyperbilirubinemia was consider a cause of CP, but now it is rarely causing CP because of improved management of hyperbilirubinemia.

Urinary incontinence is a problem children with CP, the present study reported that more than 80% of them have problem with bladder control this agreement with **fouad, (2003), El syed, (2003) and Ahmed, (2009)** who reported that poor bladder control was the comments urinary problem of CP children and added that the problem of

bladder control occurred in sixty two percent of cerebral palsy children are often the result of neurological problems.

From this study it is clear that, about two third of mothers had a lack of practice regarding feeding technique of their children with CP, table (3), as they did not follow the correct feeding technique during child feeding, such as suitable child position, using special feeding equipment, a small piece of hard food at one time, supporting jaw during feeding, and making pressure down these results are consistence with **Mohamed (2004)** who reported that there is considerable lack of mothers practice regarding feeding technique of their children with CP.

Hinchiffe (2003) added that if feeding and drinking problems of the children with CP are managed poorly, they may worsen over time and cause harmful and serious health problems, and reported that appropriate handling of children at meal times and careful management of food and feeding techniques can minimize these careful and some times to prevent them from occurring.

The present study clarified that teeth care was not practiced by the majority

of mothers for their children with cerebral palsy, which is supported by **fouad (2003) & Ahmed (2009)** who found that most of mothers had unsatisfactory practice in relation to teeth care of their children. The investigator explains that may be due to unawareness of mothers about the importance of teeth brushing for their children and to the habits of brushing their teeth after each meal.

These results go in the same with **Mohamed (2004) & Ahmed (2009)** who found in his study that oral hygiene measures were not practiced by most of mothers for their children with CP, and added that could be due to ignorance of oral hygiene. And also **Afifi (2006)** added that the incidence of dental caries has increased among CP children as a result of improper oral hygiene care or ignorance of mothers about the importance of teeth care.

Concerning the mothers practice in relation to personal hygiene (child bathing, dressing, and hair care) the present study indicated that more than two third of mothers had considerable lack of their practices regarding personal hygiene care for their children with CP. From the investigator point of

view, the source of information for the majority of mothers regarding personal hygiene care of their children was from their relatives who may have incomplete correct or incorrect information regarding personal hygiene of their child. This result is supported by **Affi, (2006) & Ahmed, (2009)** who reported that the majority of mothers had deficits in how to deal with the most aspect of their child care.

The current study revealed that the majority of mothers didn't train their CP children about toilet training. This could be due to unawareness of mothers about the importance of toilet training, and how to prevent or manage bladder and bowel problems such as urinary incontinence and constipation, that may be associated with cerebral palsy, which is in consistence with **Falvo, (2005)** who reported that bladder and bowel problems can manage through toilet training program that help child to establish a regular evacuation schedule, this was in agreement with **Ahmed, (2009)**.

The present study revealed that more than half of mothers have considerable lack of practice regarding child sleep (suitable place or special bed, suitable

child position, regular change of position during sleeping, and sleep and wake up at stable time to prevent noise and help child to sleep) from the investigator point of view this may be due to unawareness of mothers about the measures that should be adapted for their children to help them to sleep or they didn't receive any teaching program regarding the complication that occur for their children such as risk of bed sores if they didn't practice these measures during child sleep especially with children have quadriplegia, this result was supported by **Ahmed, (2009)**.

Pediatric nurse should professionally train for caring of cerebral palsy children. On other hand, improving mothers' knowledge regarding cerebral palsy children. So, it is the responsibility of the pediatric nurse as health educator to assess the self care requisites of the regarding care for their cerebral palsy children. The current study show that the majority of mothers had deficit in most aspect of item of care were neglected, after implementation there is improved in mothers' practice as the majority of them had been scored satisfactory. This

may be due to the facts that the researcher taught each mother individually about daily care, let them demonstrate most of care techniques in front of the researcher

Regarding relationship between mothers' knowledge and their level of education, it was noticed that before the program there was significant difference between illiterate and educated mothers' while this difference disappeared after program implementation. This result proved that all mothers were interested in how to gain any knowledge that proves their caring of their cerebral palsy children. Also, illiterate mothers were asking help from relative as son, husband, and sister to help them to understand every thing in handout.

The present study found that there was significant difference between mothers' knowledge and their occupation before program. While after program there was no statically significance difference between mothers knowledge and their occupation which emphasizes the high effect of the program that near the level of knowledge between employee and housewives mothers.

On investigating mothers' practice and their level of education, their was a

better practice among educated mothers compared to among illiterate. After program still there was a significant difference between mothers' practice and their level of education which emphasized the effect of mothers' level of education in their total practice. Also this study proved that there was no effect on mothers job and total level of their practice whenever before or after program implementation which proved that Egyptian mothers taken their ideal role in all different situation although of any challenges.

As regards dependence of children in daily living activities, this study results showed that, the majority of them are completely dependent on mothers in daily life activities. This result indicated that mothers need assistance from family members, and community services to provide care for their children, and to teach them how to be independent in care. **Tourk,(2000)** stated that, children with disabilities need ample opportunities to solve problems for themselves and to develop a greater sense of independence rather than dependence and a wide variety of movement activities designed to break

down the artificial limitation are that often build up around their disabilities.

The cerebral palsy affected children have to get merciful support from the family members as well as from the teachers to achieve the optimum education to their potential and other skills. This helps them to achieve their evergreen goal for the real independent life without any support from anybody else for his daily needs (**www.Cerebral PalsyTreating.com, 2010**).

Regarding problems facing mothers during caring of their children with cerebral palsy, table (2), the present study revealed that nearly more than half of mothers' complains from economical over load, followed by difficult transportations were a barrier for mothers in providing child care. Also no enough rehabilitation services in the hospitals that they attend for receiving child care such as occupational therapy. This result is congruent with **Afifi, (2006)** who that more than two third of mothers are unsatisfied from follow up services due to many barrier such as insufficient care, expenses and transportation of the child. Price & Gwin(2008) added that the long course of cerebral palsy is a

financial burden on the family expense.

The current study, table (11) revealed that there was positive highly significant correlation between mothers' total knowledge and total practice score after program. These results mean that the mothers' knowledge had an effect on their practice, as when mothers have a satisfactory knowledge level regarding their children condition; this will improve their practice regarding their daily care of their children with CP. This explanation goes in the same line with **Ahmed, (2009) & Ali, (2008)** who mentioned that when mothers provided with basic knowledge about children condition, developmental prognosis and various treatment approaches, will assist them in practicing new and healthy behaviors. In addition to **Afifi, (2006)** who insist on the necessity of availability of knowledge regarding cerebral palsy, which help in managing CP children conditions.

The results showed that there were positive highly significant correlation between the educational status of mothers with total knowledge and total practice scores after program, table (10) this result proved that all mothers were interested in how to gain any knowledge

that proves their caring of their cerebral palsy children. Also, illiterate mothers were asking help from relative as son, husband, and sister to help them to understand everything in handout.

The parent-reported quality of life for children with cerebral palsy is associated strongly with impairment. However, depending on the areas of life, the most severely impaired children (in terms of motor functioning or intellectual ability) do not always have the poorest quality of; in the moods and emotions, self-perception, social acceptance, and school environment domains, less severely impaired children were more likely to have poor quality of life (**Arnaud et al., 2008**).

Regarding physical wellbeing item of quality of life there were highly significant improvements in items related to child using their arm, legs, way to sleep, and ability to use toileting after program compared with before program.

Participation is an important health outcome for children with cerebral palsy and should be incorporated in routine clinical practice. Professionals have a role to play both at the level of addressing individual child and family

needs as well as influencing legislation and policy to ensure improved access to services and local communities (**Parkes et al 2010**).

The present study revealed that there was significant improvement regarding participation and physical health item of quality of life after program, this may due to care providing to children which enhance child health. These findings were supported by **Parkes et al (2010)** who mentioned that children with cerebral palsy and severe co-impairments were significantly less likely to experience higher levels of participation in most areas of everyday life when compared to children with cerebral palsy and no severe co-impairments.

Health and social outcomes in children who have cerebral palsy (CP) depend on several factors, including the severity of the CP, medical interventions, and the child's environment.

The children with mild cerebral palsy had greater effects on their psychosocial well-being than would be predicted by their functional disability. Functional measures were good at predicting the functional well-being but were weak at predicting the psychosocial arm of well-

being (**Pirpiris et al, 2006**).

Pain is a frequent health problem and has severe consequences both on the cerebral palsied children's QOL and their family (**Tuzun, Guven, & Ekerl, 2010**).

There was a significant negative effect of pain on the QOL of subjects. The pain also negatively affected parent's personal time and caused limitations in family activities (**Tuzun, Guven, & Eker, 2010**). Pain was associated with poor quality of life in the physical and psychological well-being and self-perception domains. Parents with higher levels of stress were more likely to report poor quality of life in all domains, which suggests that factors other than the severity of the child's impairment may influence the way in which parents report quality of life **Arnaud et al., (2008)**.

The present study that there was significant improvement regarding emotional wellbeing and self-esteem item of quality of life, this result supported with **Soyupek et al, (2010)**, and disagreed with **Russo et al, (2008)** who mentioned that children with CP experience reduced quality of life and

self-concept compared with typically developing peers.

These results suggest that children with CP do not have a lower Self-worth even though they may feel less competent in certain aspects of their self-concept. Clinicians need to account for this when deciding on management strategies and may need to educate parents and health professionals that a lower self-concept may not necessarily be associated with a diagnosis of CP (**Shields et al., 2007**).

Regarding mothers' happy, work situation and financial situation as aspect of social wellbeing domain of quality of life the present study revealed that mothers felt severe sadness, and they indicated that after having a disabled child, their social life, working life, and family relationships were all affected. Families also have financial problems this is in agreement with **Sen & Yurtsever (2007)**. So parents with a disabled child need support from professionals. Nurses have a vital role in providing support for these families

Conclusion

In the light of the study findings, it was concluded that, the mothers' knowledge and practice related to care provided to their children with CP was deficient as

none of them had a pre - program satisfactory knowledge or adequate practice. The program succeeds in improving the mothers' knowledge and practice regarding CP. After three months of implementation the program the mothers' knowledge and practice was decline but still higher than before the program regarding all items about knowledge and practice.

As regards quality of life of children, by comparing the result in the pre- and post- program implementation, the result showed slightly improvement in all dimensions of the quality of life; physical, psychological, social, and emotional post - program than pre -program.

Recommendation

The following are the main recommendation:

- Giving mother's handouts containing the teaching program and use of illustrative materials help them to gain knowledge better.
- Teaching mothers different aspects of caring of their children having cerebral palsy to improve their quality of life
- Provide mothers of children with cerebral palsy by updated pamphlets, posters and Arabic

booklets about cerebral palsy which contain an action plan suitable for each child nature in order to facilitate improving their knowledge as they considered the main member in children's care plan

- Mothers' wrong practice about caring of their children related to regularity of follow- up in physiotherapy unit for the child condition should be corrected through health teaching.
- Nurses should play a key role in the health teaching and counseling mothers about care of their children with CP.
- Nurses in the physiotherapy clinic, out patient clinic, and pediatrics department should trained well and supplied with information and training CP program as they are the main source of the mothers' information during providing the child by needed care.

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