Effect of Family Empowerment Program on Parents' Performance regarding Care of Their Children with Cerebral Palsy

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Abstract

Background: Cerebral Palsy (CP) is a multi-disorder which affects the child movement, posture, and cause sensory, cognitive, communication and behavioral problems. **Aim**: This study aimedto evaluate theeffect of family empowerment program on parents' performance regarding care of their children with cerebral palsy. **Research design**:Aquasi experimental design was used.**Setting:** The study was carried out at Neurology Out Patient Clinic at Benha University Hospital in BenhaCity.**Sample:**Convenientsample of 68 children and theirparents was included. **Three tools**were used in this study for data collection; **Tool I**: An interviewing questionnaire composed of four parts as parents' socio-demographic characteristics, children'personal data,children' medical history and parents' knowledge regarding cerebral palsy. **Tool II**:Parents reported practices questionnaireregarding care of their children with cerebral palsy**Tool III**:Family empowerment scale. **Results**: The present study denoted that there was a significant improvement in the total levels of studied parents' knowledge, practices and family empowerment pre and post program implementation and at follow-up phase. **Conclusion**: Family empowerment programwas efficient in improvingparents' performance and enhanced their empowermentregarding care of their children with cerebral palsy. **Recommendations**:Developingcontinuous family empowerment programs for parents of children withcerebral palsy to enhance their knowledge, practices and their empowerment levels.

Key words: Family Empowerment, Parents, Children, Cerebral Palsy

Introduction

Cerebral palsy (CP) is a neuromotor disease that predominantly affects movement, muscle tone, and posture. The damage to the developing brain during pregnancy through neonatal period constitutes the implicit pathophysiology. Children with CP may over time develop a numerous of secondary disorders that will have a variety of effects on their functional capabilities, even while the primary neuropathologic damage is non-progressive **(Patel et al., 2020).**

Cerebral palsy is the most frequent cause of physical impairment in children, accounting for 2–3.5 occurrences per 1000 live births globally. Currently, there are approximately 764,000 cases of CP alive, of which 500,000 are children at various stages. Every year, between 8,000 and 10,000 infants are given the diagnosis of cerebral palsy, and between 200 and 1,500 preschoolers also experience the condition. The spastic kind of cerebral palsy affected around sixty-one percent of the children with the condition. **(CDC, 2019).**

Children with CP have complicated medical demands and frequently need to be managed by a multidisciplinary team. Since, furthermore to neurological issues, they also frequently have additional conditions that are crucial in determining life expectancy because the incidence of these conditions increases the severity of the disease. Families might find it difficult to manage this because they frequently struggle to locate a primary physician to provide and coordinate care and must make severalhospital visits, which makes them disappointedwith the care they obtained **(Blair et al., 2019).**

Corresponding data obtained from the World CP Day Committee in Australia show that 1 in 3 cerebral palsy children are unable to walk. 3 out of 4 CP children suffer from discomfort, 1 in 4 of those with the condition has seizures, and 1 in 4 of those children cannot talk. Children with CP are more prone than children without the disability to experience behavioral problems (1 in 2), intellectual disability (1 in 2), and significant problems with vision (1 in 10). One in five children has sleep disorders, and one in four children have problems in controlling defecation. Last but not least, 1 children with cerebral palsy have problems with salivation control**(Siron al., 2020).**

Caring for children with CP is a burden to the family. In most cases, it results in severe psychosocial suffering and adversely impacts their quality of life. Understanding the requirements of the family will lessen their burden and help them in coping with their ambivalence **(Mohd et al.,2019).**

The family must be recognized as the center of care when using empowerment as a participatory educational model. The empowerment modelhas to be adjusted to the needs of a child with a chronic condition or handicap **(Gomez-Velasco,2019).**

Family empowerment intervention is a type of empowerment that comes from relationships among healthcare professionals and families. It fosters a sense of control over family life and results in improvements to the family's strengths, capacities, and competencies. The goal of the empowerment of a sick child and families can be to help them to effectively handle the illness. Additionally, nurses as the primary health care professionalsmust carry out interventions that concentrate on empowering families to improve member competencies so they can overcome health-related challenges**(Moriyama et al., 2019).**

Family empowerment is the perspective of a family's abilities, self-confidence, and knowledge regarding the care and development of their children with special conditions in order to attain satisfying family functioning.The accomplishment of particular results by families will be a reflection of this empowerment **(Jackson, 2017).**

The family empowerment model, which is accomplished through increasing knowledge, reinforcement, and skill development, enables children and their families to recognize their deficiencies and have the ability to modify their current circumstances. Generally, family-centered empowerment can be regarded as a remarkable method to enhance patient self-care and to engage family members **(Varvani et al., 2018).**

Pediatric nurse and community health nurse as a part of the health team have a duty to enhance the health of families and children, as well,giveassistance, health instructions and nursing care that can participate in upgrading parents' knowledge, attitudes and practices (Sayed et al., 2021)A nurse must also fulfill her responsibilities as a health care professional, an advocate, educator, and consultant, as well as an observer, an organizer, and a decision-maker. Notification about cases, family teaching

regarding disease, family reinforcement, economic assistance, feeding practices, motor skills guidance,and advocacy are all part of the care of children with CP(**Jackson& Vessey, 2017**).

Significance of the study

Cerebral palsy is considered to be the most prevalent motor impairment in children. CP is regarded as one of the major factors contributing to child handicap, mortality, and caregiver distress. More than 3.4 million children with disabilities are in Egypt. About 76.117 children in Egypt are estimated to have CP (**El-Tallawy&Farghaly, 2018**).CP is a handicap that demands extensive education, as well as availabilityof resources, knowledge, and facilities. Children suffering from CP have a variety of long-term movement deficits, and the disorder frequently impacts other developmental abilities including cognition and communication. As a result, the majority of CP clients and their families will need to get ready for a lifetime of engagement with a long-term service system. (**Kalleson et al.,2020**).

Empowerment education aims to provide patients and their families with the knowledge, skills, and elevate the level of self-awareness to effectively take part of their health-related decisions. Family empowerment is essential to create and provide services that assist and strengthen parents who are caring for a child with a disability (**Kalleson et al., 2020**). So that this research aimsto evaluate the family empowerment program on parents' performance regarding care for their children suffering from cerebral palsy.

Aim of the study:

This study was undertaken to evaluate the effect of the family empowerment program on parents' performance regarding care of their children with cerebral palsy through:

- Assessing parents' knowledge about cerebral palsy.
- Assessing parents' practices regarding care of their cerebral palsy children.
- Designing, implementing and evaluating the family empowerment program on parents' performance regardingtaking care of their cerebral palsy children.

Research hypothesis

Family empowerment program will enhanceparents' performance regarding care for their children with cerebral palsy.

Operational definitions:

Family Empowerment Model (FEM) is a framework aimed to promotes families' participation in the care and management of children with special healthcare requirements, as cerebral palsy.

Family Empowerment Scale was 34-item scale created to measure empowerment in parents and other family caregivers of children with disabilities. Based on a two-dimensional conceptual framework drawn from the literature, The first dimension shows empowerment in relation to the family, the service system, the larger community, and the political environment; the second dimension reflects how empowerment is expressed in terms of attitudes, knowledge, and behaviors.

Subjects and method:

Research design:
A quasi experimental design was used to achieve this study (one group pre/post-test and three months follow up).

Setting:
This study was carried out at Neurology Out PatientClinic at Benha University Hospital in Egypt.This setting was chosen because of higher attendance of cerebral palsy children.

Sampling:

68 children diagnosed with cerebral palsy and their parents who attended the previoussetting were incorporated in a convenient sample.

Tools of data collection: After reviewing the relevant literature, the researchers constructed three tools for the data collection process.

Tool I: An interviewing questionnaire: It was developed by the researchers and translated into understandable Arabiclanguage. It was dividedintofour parts for assessing the following:

Part   I:ParentsSocio-demographic characteristicsincluding their age, educational level, occupation, marital status, residence, income and child care giver.

Part II: **Children personal data** such as age, gender, child ranking among siblings, and number of children in the family.

Part III*: Children medical history** such as preterm birth,presenceof labor problems, typesof labor problems, post labor problems and children health problems.

Part IV: Parents'knowledge assessment;this part composed of (9) multiple choice questions covered main 9 items related to (meaning, cerebral palsy types, risk factors, causes, manifestations, diagnosis, treatment, complications and prevention).

Scoring system:

Knowledge score for each answer was given '2'score for correct and complete answer**,** '1'score for correct and incomplete answer and '0' for don't know. The total knowledge level was considered goodif the score >75%; fairif equals 50-75% and poorifthe score< 50%.

Tool II: Reported practicesquestionnaire sheet(Murphy et al., 2009 & Abd-Elsabour, 2020)the researchers modified it to evaluate the parenting practices provided for   their children such as nutritional practices (8 items), swallowing difficulty (6 items), range of motion exercise (5 items), breathing exercise (5 items), coughing exercise (5 items), hygieniccare (7 items), physical activity(5 items)and sleep(7 items) used pre and post program and follow up after three months**.**

Scoring system:

A score of '1' was given for "done" practice, while '0' was given for "not done". The overall practices score was divided into two levels: a satisfactory level ≥60% of the total reported practices score, while an unsatisfactory level was <60% of the total reported practices score.

Toolꟾꟾꟾ: Family Empowerment Scale (FES) adopted from (**Koren et al., 1992**)and modified by the researchers to assess family empowerment in the context of taking care ofchildren with special needs, ascerebral palsy. FES is consisted of (34) self- reported, instrument grouped items. It was applied three times.Firstly, preprogram implementation, secondly, post program and thirdly at the follow up phase of theempowerment program and used in three areas:

Family: Which included 12 items to assess the family's assurance in their ability to manage their child's care, and dealing with the child problem such as (when problems occur with my child, I manage them pretty well, I have trust in my abilities to support my child's growth and development.,I am aware of what to do if my child has issues., When dealing with my child, I focus on the positive things as well as the problems …....etc.

Child services: which included 12 items to assess the family's access to resources and healthcare services, such as (I believe that I have a right to approve all services provided to my child, I know the steps to do when I am concerned my child is getting inadequate services, I ensure that professionals aware of my views regarding the services my child requires., I have the ability to make good decisions about what services my child needs …etc.

Participation in the community: which included 10 items to assess the family's involvement in treatment decisions, their ability to advocate for their child's needs, such as (I believe I can contribute in improving services for children in my community, I realize   how the service system for children is organized, I am aware of what the special education laws say about parental and child rights. …..etc.
Scoring system:

The final score is the sum of the three areas of the scale. Each response received a score between 0 and 2, based on a three-point

Likert-type scale. in which never = 0, sometimes = 1, and always = 2.A higher score reveals comparatively increased empowerment in each relevant area. All items are scored in the same direction; no item scores are reversed. Total scores of family empowerment scale were ranged from 0 to 68. Therefore, the empowerment level will be divided into three categories: high family empowerment score (≥75%), moderate family empowerment score (60<75%), and low family empowerment score (<60%).

Administrative process

A formal letter from the dean of the nursing faculty at Benha University was submitted to the director of Benha University Hospital to take written permission from the hospital to conduct the study. The letter outlined the study's objectives and requested the annual statistical number of children suffering CP who come to the hospital.

Ethical consideration:

The researchers explained the aim of the research to each parent to get their informed consent to contribute in the study; both the parents and children have the free choice to withdraw from the study at any point. The parents were also told by the researchers that all data was used exclusively and confidentially for research purposes.

Tool development

After reviewing the relevant literature, the researchers developed data collecting tools. These tools were then written and translated into clearly Arabic to be suitable for parents understanding.

Tools validity

A group of 5 experts, two from the field of Community Health Nursing and three from the field of Pediatric Nursing revised the tools to ensure their validity in relation to their content, relevance, clarity applicability, and comprehensiveness.

Tools reliability:

Cronbach's Alpha coefficient test was utilized to test reliability which exhibited that the tools included homogenous items as indicated by the moderate to high reliability of tools. The internal consistency for knowledge was 0.858,for reported practices sheet was0.907 and for family empowerment scale was 0.826.

Pilot Study

It was done on 10% of study sample which included (7) parents. It was conducted to make sure that the study tools were understandable and easy to apply. Furthermore, to discover any limitations and problems that the researchers might find while gathering data. Since no modifications were made, the pilot study's parents were also included.

Data collection:

The study was carried out through four main phases. assessment, planning, implementation, and evaluation. These phases took place from the start of October 2020 to the end of June 2021, covering a period of six months for family empowerment program followed by three months for follow up. The researchers went to the previous setting one day/week from 9a.m to 1.00 pm because the children with neurological disorders were attending to the neurology outpatient clinic at Sunday.

The study was conducted through:

A. Preparatory phase:

In order to achieve the research aim, the researchers firstly reviewed national and international literature regarding the several aspects of the research problem which helped the researchers to be acquainted with the dimension and severity of the problem and guide the researchers to develop tools of data collection.

B. Assessment phase:

Parents were interviewed during the assessment phase to obtain baseline data. The researchers greeted each parent, addressed the objectives, time line, and activities of the study, and obtained informed consent at the beginning of interview. the researchers were available one day every week (Sunday) from 9.00 am to 1.00 pm.The researchers met the parents and their children at a separate place at a wide hall in front of the clinic in the first floor of the hospital. The assessment phase took nearly 8 weeks. The researcher spent approximately 15

minutes gathering the data for each child with cerebral palsy. The studied parents were asked to complete the questionnaire in order to assess their knowledge and reported practices. It required 20 - 30 minutes.The telephone numbers of parents were taken. Depending on the admitted parents who agreed to participate in the study, the number of parents who were interviewed was identified.

C. Designing the program:

The researchers designed the empowerment program in simple Arabic language utilizing the family empowerment scale depending on the parents'requirements indicated in the assessment phase and in light of the relevant literature. Researchers confirmed the number of sessions, contents, the various teaching methods, and the media to be used in the program based on parents' levels of understanding. The telephone calls schedules were performed for follow up. Following that, the program's objectives were created as follows:

General objectives

The general objective of the empowerment program was to improve parents' performance toward care of their children with CP.

Specific objectives:

After the completion of the familyempowerment program, the studied parents should be able to:

A-Knowledge and understanding skills

- Define cerebral palsy.
- Mention riskfactors or causes of cerebral palsy.
- Illustrate types of CP.
- Mention manifestations of CP.
- Discuss types of treatment of CP.
- Discuss parent role for child with CP.
- Define family empowerment.
- Discuss importance and value of family empowerment.
- Discuss dimensions of family empowerment.
- Identify their abilities to use services, deal with child problems and advocate for the child rights.

- Illustrate available services incommunity for the child with CP
- Discuss importance of parent's involvement in improving services of children.

B- Practical skills

- Demonstrate proper nutrition related practices for the child.
- Apply steps to manage swallowing difficulty.
- Demonstrate and teach child steps of breathing and cough exercise
- Perform appropriate range of motion exercise for child accordingchild'sabilities.
- Demonstrate steps of child hygiene.
- Utilize the child abilities for appropriate physical activities.
- Utilize available services for proper care of the child and deal with child problems.
- Apply steps that help the child for good sleep.
- Utilize abilities of each family members for providing proper care for the child.

D. Implementation phase

The empowerment program was implemented during the implementation phase. It included (8) scheduled sessions. Each session for the small group of parents, which included 2-3 parents, lasted between 30 and 40 minutes. The parents' attendance affects how many groups are interviewed each day. Severalteaching methods, including lectures, group discussions, questions and answers, demonstration, redemonstration and power point presentations were employed. On the first day of the empowerment program, all parents received appropriate teaching media, included an educational booklet. A brief overview to the empowerment program and its aimwas done at the beginning of the first session. Every session started with a brief orientation of the prior one. The empowerment program was implemented through the following stages:

-**Stage I (knowledge improvement):** The researchers provided the theoretical knowledgeand understanding skills for parents about CP such as meaning, CP types, risk

factors, causes, manifestations, diagnosis, treatment, complications and prevention.

- Stage II (self-efficiency elevation): The practical skills were explained for parents which included nutritional practices, swallowing difficulty practices, hygienic care, range of motion exercise and breathing and coughing exercise, physical activity and sleep.

- Stage III (self-esteem enhancement):the researchers advised the parents to ask questions about what they want to know from the researchers regarding CP and care of their children to be discussed in the next session. The pervious stages were implemented through the program sessions, each session started by a summary of the previous one and objectives of the new session. Total number of sessions for the parents was 8 sessions 4 sessions for theoretical part and 4 sessions for practice part. Each group received the same sessions.

Theoretical part for parents included three sessions as the following:

- **Two sessions regarding CP:**

The first sessionincluded explanation aboutmeaning, causes, types, manifestations, and treatment of cerebral palsy.

The second session included complications and prevention of CP, role of parents toward their children with CP and available services for children with CP.

- **Two sessions for family empowerment**

One session covered meaning, importance, values, aim and dimensions of family empowerment. and **another session**covered explanation of family empowerment scale, and the relationship between parent performance and family empowerment regarding children with cerebral palsy.

Practical part for parents included three sessions as the following;

- **The first session** of practical part included nutritional practices and swallowing difficulty practices.
- **The second session** included range of motion exercise and physical activity.
- **The third session** included breathing and coughing exercise.

- **The fourth session** included hygienic care and sleep related practices.

E. Evaluation phase:

After program implementation, the efficacy of the empowerment program was evaluated using the same tools which were used preprogram. Then follow up after three month was done through other visits to the neurological outpatient clinicapplying the similar previous tools.During the period of follow-up the researchers made telephone calls(one call per week for each parent) to ensure parents compliance with care of their children. Each call continues for 10 minutes or varies according parent's needs.

Statistical analysis:

The data were coded for entry, analyzed and tabulatedthrough Statistical Package for Social Science(SPSS), version 22. Descriptive statistics were used to present the data as frequencies, percentages, means, and standard deviation. To calculate the statistically significant differences, chi square tests and the Pearson correlation coefficient were utilized. A P-value of less than 0.05 was considered significant, while considered highly significant if less than or equal to 0.001.

Results:

Table (1) shows that 29.4% and 41.2% of fathers and mothers respectively were aged 30<40 years with mean age 36.79±6.93years for fathers and 28.45±6.16 for mothers. Also, 54.4% and 42.6% of fathers and mothers respectively had university education. Additionally, 50% and 41.2% of fathers and mothers respectively were employees, 35% of them had adequate income and 68% of care givers were child mother.

Table (2) indicates that 70.6% of children were in the aged of 1<5years with mean age 4.21±2.41years. Also 61.8% were females, 48.5% of the children were the second in ranking among siblings, and 42.7% of families had two children ranking among siblings, and 42.7% of families had two children.

Table (3) clarifies that 89.7% of children had preterm birth, 55% had labor problems and 78.2% were low birth weight. While 51.5% of children had post labor asphyxia, 69.1 and 61.8 % of them were suffering from movement problems and nutritional problems respectively.

Table (4) illustrates that the studied parents mean score of knowledge improved from 5.29±4.05 preprogram to 15.50±3.44 post program implementation and to 13.88±4.70 during follow up phase moreover, there was a highly statistically significant differences between knowledge ofstudied parents pre and post program implementation.

Figure (1) demonstrates that 73.5% and 70.6% of the studied parents had good total knowledge level post program implementation and at follow up phase respectively in comparison with 4.4% preprogram implementation. While 7.4% and 8.8% the studied parents had poor total knowledge level post program implementation and at follow up phase respectively compared with 53.0% preprogram implementation.

Table (5) illustrates that the studied parents mean score of nutritional practices elevated from 2.63±2.53 preprogram to 7.33±1.38 post program implementation and to 6.88±2.48 at follow up phase. While the mean score of hygienic care practices of the studied parents increased from 2.04±1.26 preprogram to 6.48±1.04 post program implementation and to 6.35±2.21 at follow up phase. Also there was a highly statistically significant differences between studied parents' total reported practices items pre and post program implementation (p<0.001).

Figure (2) portrays that 79.4% and 72.1% of the studied parents had satisfactory total practices level post program implementation and at follow up phase respectively compared with 19.1% preprogram implementation. While 20.6% and 27.9% of the studied parents had unsatisfactory total practices level post program implementation and at follow up phase respectively compared with 80.9% preprogram implementation.

Table (6) illustrates that the mean scores of total family levels of the studied parents increased to 21.10±2.35and 20.25±2.82 post program implementation and at follow up phase respectively compared with 6.25±2.75 preprogram implementation. While the mean scores of total child services levels increased to 20.67±3.79 and 19.17±1.96 post program implementation and at follow up phase respectively compared with 5.08±2.61 preprogram implementation. While mean score of total community involvement level 4.36±1.74 preprogram compared to 17.89±2.75 and 17.64±3.86 respectively post program and at follow up phase. In addition, there was a highly statistically significant difference in relation to studied parents' total family empowerment pre and post program implementation (p<0.001).

Figure (3): clarifies that 54.4% and 50% of the studied parents had high total family empowerment level post program implementation and at follow up phase respectively compared with 8.8% preprogram implementation. While 14.7% of the studied parents had low total family empowerment level post program implementation and at follow up phase respectively compared with 51.5% preprogram implementation.

Table (7) shows that there was a positive statistically significant correlation between studied parents' total knowledge and total practices preprogram implementation and at follow up phase(p<0.05). While there was a highly positive statistically significant correlation between total knowledge and total practices post program implementation(p <0.001).

Table (8) Shows that there was a positive statistically significant correlation between total knowledge and total family empowerment pre and post program implementation(p<0.05) and at follow up phase(p<0.001). While there was a positive highly statistically significant correlation between studied parents' total family empowerment and total practices pre and post program implementation and at follow up phase(p<0.001).

Table (1): Frequency distribution of studied parents regarding their socio-demographic characteristics (n=68).

Socio Demographic characteristics	Father		Mother	
	No	%	No	%
Age/yrs				
25<30	22	32.4	34	50.0
30<40	20	29.4	28	41.2
>=40	26	38.2	6	8.8
Min –Max	27-45		21-40	
	Mean ±SD 36.79±6.93		Mean ±SD 28.45±6.16	
Educational level				
Read and write	6	8.8	6	8.8
Basic education	6	8.8	13	19.1
Secondary	19	27.9	20	29.4
University	37	54.4	29	42.6
Occupation				
Free work	34	50.0	0	0.0
Employee	34	50.0	28	41.2
Housewife	0	0.0	40	58.8
Marital status				
Married	55	80.9		
Divorced	13	19.1		
Residence				
Rural	32	47.1		
Urban	36	52.9		
Income				
Inadequate	33	48.5		
Adequate	35	51.5		
Child care-giver				
Father	50	73.5		
Mother	68	100.0		
Grandparent	29	42.6		

Table (2): Frequency distribution of studied children regarding their personal characteristics (n=68).

Children personal data	No	%
Age/yrs.		
1<5	48	70.6
5<10	16	23.5
10-12	4	5.9
Mean ±SD 4.21±2.41		
Gender		
Male	26	38.2
Female	42	61.8
Child ranking among siblings		
First	28	41.2
Second	33	48.5
Third	7	10.3
No. of children in the family		
1	19	27.9
2	29	42.7
3	13	19.1
>4	7	10.3

Table (3): Frequency distribution of studied children regarding their medical history (n=68).

Medical history	No	%
Preterm birth		
No	7	10.3
Yes	61	89.7
Presence of labor problem		
No	13	19.1
Yes	55	80.9
***Types of labor problem**		
Hypoxia	26	47.3
Labor injuries	35	63.6
Hydrocephalus	27	49.1
Low birth weight	43	78.2
***Post labor problems**		
Brain hemorrhage	15	22.1
Encephalitis	26	38.2
Infection	26	38.2
Asphyxia	35	51.5
Not present	14	20.5
***Children health problems**		
Swallowing difficulty	41	60.3
Movement problems	47	69.1
Nutritional problems	42	61.8
Shortness of breath	21	30.9
Communication problems	20	29.4
Vision problems	13	19.1
Hearing problems	14	20.6
Constipation	36	52.9

*The result was not mutually exclusive

Table (4): Mean and standard deviation of studied parents regarding their total knowledge through the program phases

Items	Preprogram		Post program		Follow up		t1	p-value	t2	p-value
	Mean	±SD	Mean	±SD	Mean	±SD				
Total knowledge	5.29	4.05	15.50	3.44	13.88	4.70	15.994	.000**	1.367	.051

** Highly statistically significant difference p<0.001
t1 paired t test between parents' knowledge pre and post program
t2 paired t test betweenparents' knowledge post program and at follow up after 3 months

Figure (1): Percentage distribution of studied parents regarding their total knowledge level through the program phases (n=68)
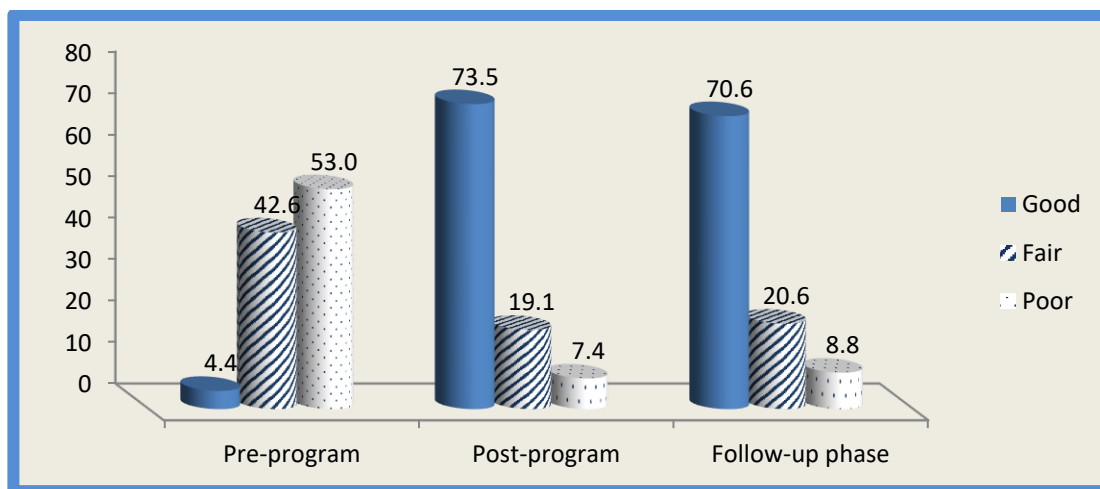

Table (5): Mean and standard deviation of studied parent regarding their total reported practices items through the program phases.

Items	Preprogram		Post program		Follow up		t1	p-value	t2	p-value
	Mean	±SD	Mean	±SD	Mean	±SD				
Nutritional practices	2.63	2.53	7.33	1.38	6.88	2.48	14.712-	.000**	1.229	.060
Swallowing difficulty	2.08	1.44	4.79	1.56	4.26	1.83	10.913-	.000**	1.546	.053
ROM exercise	1.75	2.05	5.30	1.10	4.89	2.03	13.583-	.000**	0.618	.210
Hygienic care	2.04	1.26	6.48	1.04	6.35	2.21	26.215-	.000**	1.132	.071
Breathing exercise	.50	1.22	4.48	.81	4.26	1.48	24.256-	.000**	1.796	.052
Coughing exercise	.97	1.00	4.39	1.03	4.09	2.05	21.416-	.000**	0.341	.061
Physical activity	1.14	.71	4.32	1.08	4.22	1.46	21.896-	.000**	0.714	.471
Sleep	2.00	1.28	5.60	.67	5.29	1.64	20.533-	.000**	0.630	.321
Total practices	13.13	8.59	42.73	7.59	40.57	14.05	23.647-	.000**	1.604	.621

** Highly statistically significant difference p<0.001

t1 paired t test between parents' practices pre and post program
t2 paired t test betweenparents' practices post program and at follow up after 3 months

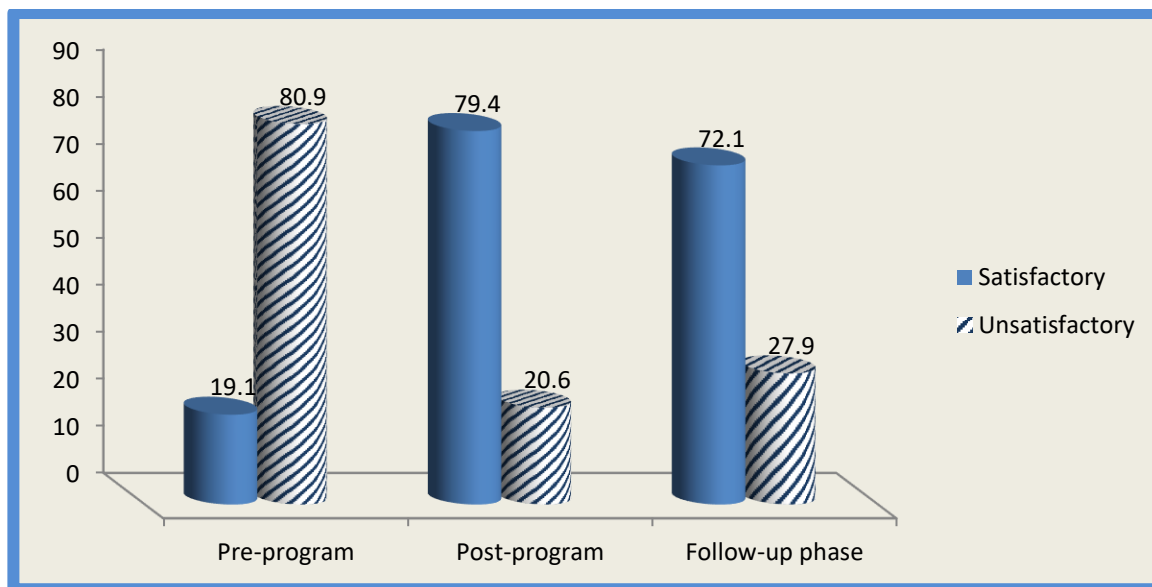**Figure (2): Percentage distribution of studied parents regarding their total practices level through the program phases (n=68)**

Table (6): Mean and standard deviation of studied parent regarding their total family empowerment through the program phases

Items	Preprogram		Post program		Follow up		t1	p-value	t2	p-value
	Mean	±SD	Mean	±SD	Mean	±SD				
Total Family level	6.25	2.75	21.10	2.35	20.25	2.82	32.901	.000**	1.458	.061
Total Child Services level	5.08	2.61	20.67	3.79	19.17	1.96	25.486	.000**	1.107	.059
Total Community/ political participation level	4.36	1.74	17.89	2.75	17.64	3.86	31.718	.000**	0.666	.053
Total	**15.70**	**5.21**	**60.04**	**7.95**	**58.36**	**7.12**	**34.322**	**.000****	**1.887**	**.051**

**** Highly statistically significant difference p<0.001Not significant p>0.05**

t1 paired t test between parents' empowermentpre and post program

t2 paired t test betweenparents' empowerment post program and at follow up after 3 months

Figure (3): Percentage distribution of studied parents regarding their total family empowerment level through the program phases (n=68)
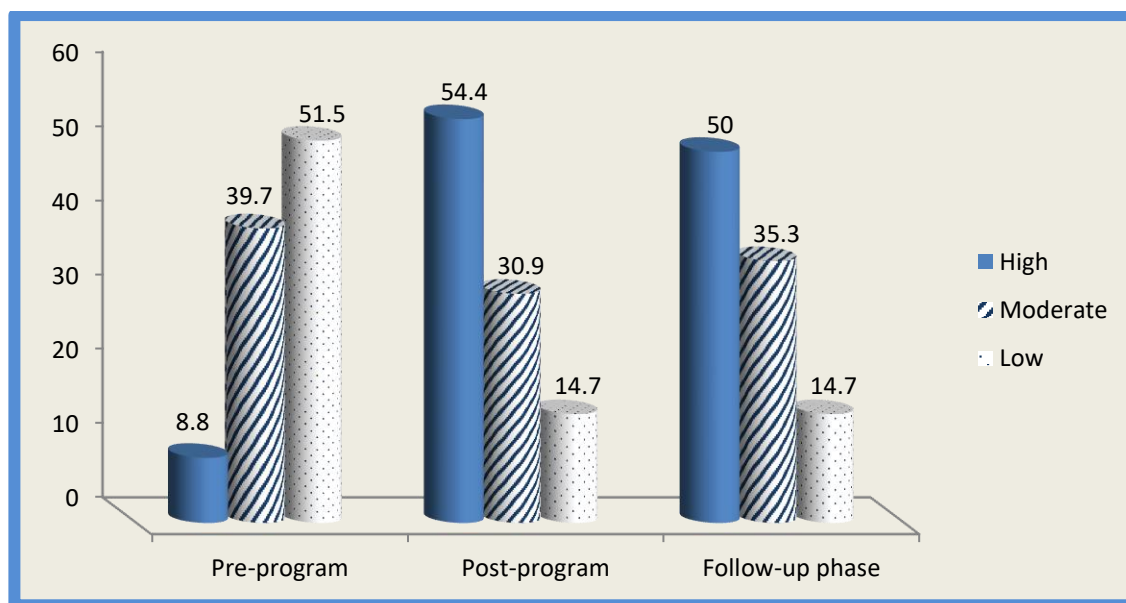

Table (7): Correlation between total knowledge and total practices among studied parents through the program phases.

Items	Total knowledge					
	Preprogram		Post program		Follow up	
	r	p-value	r	p-value	r	p-value
Total practices	.268	.027*	.750	.000**	.333	.006*

** Highly statistically significant p<0.001   *Statistically significant p<0.0

Table (8): Correlation between total family empowerment, total practices and total knowledge among studied parents through the program phases.

Items	Total family empowerment					
	Preprogram		Post program		Follow up	
	r	p-value	r	p-value	r	p-value
Total practices	.587	.000**	.884	.000**	.697	.000**
Total knowledge	.312	.010*	.550	.021*	.719	.000**

** Highly statistically significant p<0.001   *Statistically significant p<0.05

Discussion

Children with CP require diverse care due to obvious impairments in their sensory, communicative, intellectual, and motor functions. Consequently, a variety of issues and challenges along with high levels of stress, sadness, and exhaustion were regularly confronted by caregivers(**Bunning et al., 2017**)Empowerment is referred to as acquiringmore control over life and an outcome reflected on different levels: personal, interpersonal and political or social change (**Kalleson et al., 2020).** The present studyaimed toevaluate the effect of the family empowerment program on parents' performance regarding care of their children with cerebral palsy.

Regardingstudied parents' sociodemographic characteristics, the present study showed that less than one third of fathers and more than two fifths of mothers were aged 30<40 years with mean age 36.79±6.93years for fathers and 28.45±6.16 for mothers and more than two thirds of child caregiver were mothers. These results were supported by **Maggioni & Araújo, (2020)** who carried out a study about practices on feeding children with CP and reported that almost one third of studied caregivers aged from 29 to39 years and majority of caregivers were mothers. Additionally, these findings were in the same line with**Donkor et al., (2019)** who studiedthe nutritional status of children with cerebral palsy in Ghana and found that, majority of caregivers were the mothers of children and more than half of them were unemployed.

Corresponding to educational level of studied parents, this study illustrated that more than half of fathers and more than two fifths of the studied mothers had university education, these findings disagreed with **Warmbrodt, (2019)** who conducted a studyon child nutrition with cerebral palsy and denoted that most of (90%) caregivers had university education.

Concerning personal data of the studied children**,** the present study clarified that more than two thirds of children were in the age group of 1<5years with mean age 4.21±2.41years. This finding was compatible with **Mahmoud &Sabea, (2020)** who conducted a study on mothers of children with cerebral palsyand showed that 51.7%of the children were aged 4±5 years with the mean age 4.08 ± 0.77 years. This outcome was in agreement with A**lruwaishedet al., (2020)** who carried a study in Riyadh City regarding caregivers of CP children knowledge and attitude and found that the median age of the children in his study was 4.50 years (IQR = 4.0–6.0).

Additionally, this existing study found that more than three fifths of children were females, which was inconsistent finding with **Mahmoud &Sabea, (2020)** who mentioned that, more than half of children with cerebral palsy were males. Also, the previous result contradicted with **Hameed et al., (2012)** who performed a study concerned with care provided to hemiplegics cerebral palsy children by their caregivers and stated that both sexes had equal cerebral palsy occurrence.

As regard ranking of child in his family less than half of the children were the second in ranking among siblings, and less than half of families had two children. This result was inconsistent with **Hashem & Abd El Aziz, (2018)** who studied the effect of improving mothers care for their children with CPand demonstratedthat more than half of studied children were the family's first child.

Concerning medical history of studied children, the current study revealedthe majority of children had labor problems and more than three quarter were low birth weight. While more than half of children had post labor asphyxia, more than two thirds and more than three fifths of them were suffering from movement problems and nutritional problems respectively. This might be attributed to birth asphyxia, which is characterized by blood supply and oxygen loss and puts the infant at a significant risk for brain hypoxia and acidosis due to an elevated blood carbon dioxide level. One of the consequences of this is hypoxia ischemic encephalopathy which can cause braindamagewhich is one of the leading causes of newborn death or serious postnatal neurological disabilities like cerebral palsy. These findings were supported by **Hegazy &Mekhamier, (2017)** inthe study aboutself-learning package for mothers of children with CPand found that child labor and pregnancy-related causes of cerebral palsy were the most frequently reported in her study. This outcome also agreed with **Barakaet al., (2019)** who conducted a study regarding mothers, knowledge and practice about quality of

life for their children with cerebral palsy and found that the majority of children (85.3% &88.3%) had asphyxia and eating difficulties respectively and 43.9% had difficult labor.

Regarding mean and standard deviation of studied parents regarding their total knowledge over all the program phases the present study confirmed that the mean score of knowledge of the studied parents increased from 5.29±4.05 preprogram to 15.50±3.44 post program implementation and to 13.88±4.70 at follow up phase. This conclusion may be rationalized by the fact that time usually has an impact on knowledge retention. This finding reinforced by **Baraka et al., (2020)** who revealed that, most of mothers had poor knowledge before educational intervention program. On the other side immediately after implementation of educational program, the mothers' total knowledge scores were good. In addition, a month following the educational program, mothers' total knowledge scores were decreased even though around three-quarters of them had good scores.

Additionally, the current study showed that, there was a highly statistically significant differences between studied parents' knowledge pre and post program implementation. This might be a result of the program's content being created based on parents and children needs.

Regarding parents 'total knowledge level throughout the program phases. This study approved that nearly to three quarters and more than two thirds of the parents had good total knowledge level post program

implementation and at follow up phase respectively compared with minority of them preprogram implementation. From the view of point the researchers this may be due to the effective program that used simple language, pictures and use of straightforward communication techniques, and preparation of educational program materials based on pretest defect. This result agreed with **Baraka et al., (2019)** who illustrated results regarding total scores of mothers' knowledge about cerebral palsy indicated that most of mothers (88.33%) had poor knowledge before educational program while, all of them (100%) and nearly three quarters (71.67%) had good knowledge immediately and one month after educational program respectively with statistically significant differences (p<0.001). Also, the existing study result was supported by **Afifi et al., (2018)** who reported in their research that mothers good score was higher after program implementation than pre and follow up, and highlighted the beneficial impact of intervention programs on mothers' knowledge.

This study showed that minority of studied parents had poor total knowledge level post program implementation and at follow up phase respectively compared with more than half of them preprogram implementation. This finding was in disagreement with **Hashem & Abd El Aziz (2018)**, theysaid that Before the teaching program, the majority of the studied mothers had unsatisfactory knowledge, but after six months of the program, all of them had satisfactory knowledge regarding cerebral palsy and how to care for associated problems in their children.

According to reported parents' practices regarding child nutrition showed that the mean score of nutritional practices of the studied parents improved from 2.63±2.53 preprogram to 7.33±1.38 post program implementation and to 6.88±2.48 at follow up phase. The present study finding approved with **Donkor et al., (2019)** who provoked that the feeding practices of mothers was improved after the training program.

The existing study explained that the mean score of hygienic care practices of the studied parents increased from 2.04±1.26 preprogram to 6.48±1.04 post program implementation and to 6.35±2.21 at follow up phase. This finding was in agreement with**Akhter et al., (2018)** who explained that, trained caregivers had positive effect on daily living skills of CP children and enhancement of hygiene measures related to oral care.

In addition, there was a highly statistically significant differences between studied parents' total reported practices items pre and post program implementation (p<0.001). The finding agreed with **Chang et al., (2019)**who studied the effect of virtual reality rehabilitation on upper extremity function of children with CP who showed that trained caregivers positivelyaffected daily living skills of children suffering from CP.

The current study found that, there was a highly statistically significant difference in relation to studied parents' total family empowerment levels pre and post program implementation (p<0.001). This result reflected a positive effect of designed family empowerment program.

This result agreed with **Burton et al., (2018)** who shown an improvement in parental empowerment scores on the FES (Family Empowerment Scale) from pretests to post tests.

The current study wasin linewith **Golubović et al. (2020),** who performed a study in the Serbian Context regardingEmpowerment of families having child with a developmental disability and reported that the highest levels of parental empowerment were detected in the Family domain (M = 3.9; SD = 0.6), while the lowest were in the community domain (M = 2.9, SD = 0.9) and noted that parents of children with developmental disabilities requireassistance and empowerment to actively engage in working with their child and making decisions related to his/her development to utilize all community – based resources available.

Regarding to correlation between studied parents' total knowledge and total reported practices through the program phases, the present study showed that there was a positive statistically significant correlation between studied parents' total knowledge and total practices preprogram implementation and at follow up phase. This outcome was anticipated because better practices with their children were implemented as a result of mothers' increased knowledge of cerebral palsy.The findings of the present study are consistent with those of **Rashad et al., (2021)** who carried out a study at Zagazig University Hospitals about maternal training program on improvement of care provided to their children with CP and found a statistically significant positive correlation between

mothers' knowledge and practices about the care of children with cerebral palsy.

As regard correlation between total family empowerment, total practices and total knowledge among studied parents through the program phases. While there was a positive statistically significant correlation between total knowledge and total family empowerment pre and post program implementation and at follow up phase. This result agreed with **Douglas et al., (2017)** who assessed the information needs of parents of infants with an intellectual disability and found that parents also need to gain knowledge to reduce stress, adapt to the child's condition, and be able to do proper parenting forchildren ID in the home environment.

According to the existing study there wassignificant correlation between studied parents' total family empowerment and total practices pre and post program implementation and at followup phase. This outcome supported by**Wakimizu et al., (2017)** who performed a study in 78 Japanese families raising children with developmental disabilities who stated that family empowerment indicates a process wherebyfamilies empower themselves by attaining knowledge, skills and resources that help them to increase control over their own lives and activities of daily life. From the researchers' point of view to help families deal with health issues, it is important to continuously provide them with information and support. Empowerment also involves a process of change that moves the families from ignorance to awareness (the knowledge aspect), from awareness to willingness (the attitude aspect), and from desire to be able to carry out the expected behavior.

Conclusion

The empowerment program succeeded to improve parents' knowledge and practices regarding care of their children with cerebral palsy. Also, empowerment program was efficient in enhancing parents' empowerment levelsand their abilities to deal with the child problems, utilizing available services,participating in the community and make decisions relevant to child care and services.So the aim and hypothesis were fulfilled.

Recommendations:

Based on the result of the current study, the following recommendations are suggested:

- Developing continuous familyempowerment programs for parents of children with CP to enhance their knowledge, practices and their empowerment levels.

- Dissemination of the educational booklet to all neurological outpatient clinics at Benha City to be provided to all newly admitted children.
- Further researches about CP in various settings with a larger sample size.

Study limitations

Noise and crowding at outpatient clinics were limitations for the researchers, and some sessions took longer than expected due to frequent interruptions.

Acknowledgments

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