

Effect of Empowerment program for caregivers on Quality life of children with Cerebral palsy

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Abstract

Background: Cerebral palsy (CP) is a multi-disorder which disturbs ability of child to move, sustain posture and balance. Quality of life is increasingly recognized as a major factor in determining a child's health and well-being. There are many ways to enhance the quality of life for children with (CP), such as empowering the caregivers. **Aim:** to evaluate the effect of empowerment program for caregivers on quality life of children with cerebral palsy. **Design:** A quasi-experimental research design (one group pre/posttest) was conducted at neurology out- patient clinic of Children Hospital at Ain shams University Hospital. **Sample:** A purposive sample consisted of 75 children and their caregivers at the previously mentioned setting. **Tools:** Four tools were used as children and their caregivers' demographic characteristics, activity of daily living, child quality of life inventory and family empowerment scale. **Results:** revealed that 74.7% of the studied children were partially dependent at total activities, while 50.7% of them were independent at post program, detected through p value <0.01. Also, revealed that there was slight significant difference related to physical, emotional and social function at pre and post program at p value <0.05. But, there was no significant difference between mean score at pre and post program related school function at p value >0.05. **Conclusion:** There was high significant difference between mean scores at pre and post empowerment program for caregivers of children with cerebral palsy at p value <0.01. Empowerment program for caregivers had positive effect on quality life of their children. **Recommendation:** Preparing continuous empowerment program for caregivers of children suffered from cerebral palsy.

Keywords: Empowerment, Quality life, Cerebral palsy, Children.

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Introduction:

Cerebral palsy (CP) is a multi of disorders due to brain injury or insult at prenatal, perinatal, and postnatal time caused main developmental disability which has undesirable impact on child and their caregivers throughout child life. It is characterized by incapability to control motor functions, positioning and balance, and may disturb development of a child through affecting ability of children to explore, learn, speak, and

become independent *Deon and Gaebler-Spira (2018) & Davis et al., (2019).*

Prevalence of CP over world about 2–3.5 cases per 1000 live births, so considered most common cause of physical impairment at childhood. Nearby live 764,000 CP patients at this time, 500,000 of those patients are children at different stage. Eight to ten thousands infants are diagnosed with cerebral palsy every year and 1, 200 to 1,500 children at pre-school stage

suffered from CP per year. About 61% of all children with cerebral palsy suffered from spastic type, so considered most common one *CDC, (2019)*.

Children suffered from CP need multifaceted care because noticeable impairment at sensory, communication and intellectual plus motor function impairment. Therefore, caregivers frequently faced a range of problems and difficulties as well as high levels of stress, depression, anxiety and fatigue *(Bunning, et al., 2017)*. Empowerment of children with CP and their caregivers can help them deal efficiently and manage complications of CP to achieve a higher level of quality of life (QoL). Also, it denotes to the opportunities provided by experts to members of family for enhancing their present capabilities, competencies meanwhile acquires a new talents for meeting their needs *(Subandi, 2016)*. However, role of the caregiver is vital, mainly as the health provider for children and their families. Therefore, every mother who has a CP child requires skills, knowledge, awareness and high confidence in her skills.

Pediatric nurse and community health nurse as a medical professional have a responsibility to promote the health of families and children also provide services to children as support, health teaching and nursing services that can contribute to enhance caregivers' knowledge, attitudes and skills in caring for their child *(Hwang, et al., 2016)*. Moreover, nurse is expected to fill all of her role as care provider, advocate, teacher and Counselor, observer, organizer and decision-maker **However**, management of children with CP includes referral of

suspected cases, family education about diagnosis, family support, financial aid, nutritional management, movement and mobility management, communication management and advocacy *(Jackso and Vessey, 2017)*.

Magnitude of the study:

Cerebral palsy considers the further most common motor incapacity in childhood. It is considered as one of the leading causes to child morbidity and mortality and psychological stress for caregivers. In Egypt, there are more than 3.4 million handicapped children. The estimation of children with CP in Egypt is about 76.117 *(El-Tallawy and Farghaly, 2018)*. Caregivers for children with cerebral palsy need information about practical skills to deal with every day problem *Taylor, (2018)*. Therefore, empowerment education program and effective management can improve the quality of life for CP child and their caregiver. Moreover, improve functionality and capabilities toward independence and enhancing child and care provider interaction, also, providing family support *(Hamel and Danilson, 2017)*.

Aim of study

This study aimed to evaluate the effect of empowerment program for caregivers on quality life of children with cerebral palsy through:

1. Assessing knowledge and practices of caregivers regarding to care of their children with CP
2. Assessing activity of daily living for child with CP.

3. Design, implement & evaluate empowerment program for caregivers on improving quality of life of their children with CP

Research hypothesis:

Empowerment program for caregivers will improve quality of life of children with cerebral palsy.

Conceptual frame work:-

The conceptual framework of this study was to choose a combination between two theories 1- learning theory to promote critical thinking, problem solving, and parent support (*Knowles, 1984*). 2- Theory of change (ToC) which permitting the caregiver to advance care and support for their child, as well as understanding of rights of children, moreover, to share their experience and knowledge with family who response to caring of children (*Goody, 2005*).

Subjects and methods:-

Research design:

A quasi-experimental design was used to accomplish the aim of the study (one group pre/posttest)

Settings:

The study was conducted at neurology out- patient clinic of Children Hospital affiliated to Ain shams University Hospital. This setting is selected due to the high attendance of children with cerebral palsy on this setting and also serve the biggest region.

Sampling:

A purposive sample involved 75 children and their caregivers from the total number 220, who attended to previously mentioned setting within a

period of six months from the first of June and to last November 2020 with confirmed diagnosis of cerebral palsy was used in this study. The calculation of sample size done based on the power analysis.

The sample size was calculated based on:

$$N = \frac{N \times p(1-p)}{\{N-1 \times (d^2 \div z^2)\} + p(1-P)}$$

- Type I error with significant level (α) = 0.5.
- Type II error by power test (1-B) = 95%.

The minimum sample were (75) cases (*Suresh and Chandrashekar, 2012*).

Inclusion criteria:

Age of child patients range between 1-12 years with moderate grade of CP from both genders.

Exclusion criteria:

Children suffering from extra disorders

Tools of data collection:

Four tools were designed by the researchers after reviewing the related literature review.

Tool I: A structured interview questionnaire (pre/posttest) was designed in a clear Arabic language based on (*Dambi, et al., 2016*) and experts' opinions. It contained of four parts:

Part I:

1. **Characteristics** of caregivers such as age, sex, educational status, occupational, marital status family,

crowding index and family income LE/month.

2. **Characteristics of children** such as age, ranking, gender, education level, past history, residence, and history of family, types of cerebral palsy and its complication.
3. **Caregivers' knowledge about CP** such as meaning, causes, and problems associated to CP.
4. **Caregivers' knowledge about care of children with cerebral palsy,**

Include the following items: movement (7items), level of independence (6 items), difficult in swallowing (4 items), and difficult in language (5items)

Scoring system

A correct answer take one point while incorrect answer as zero, score from 0 to < 50 denoted poor knowledge, 50 < 75 was average while score from 75 ≤ 100 was good level.

5. **Assessment of activity of daily living for cerebral palsy child** which include 9 items such as Nutrition, Mobility, Walking, Clothing, Bathing, Evacuation, Contact with others, Mouth care and Sensory activity (hearing, vision and communication)

Scoring system

Each item of the daily activities has score according to level of dependency as: full dependent (1) partial dependent (2) independent (3) score. The total score of the daily activities performance is 36. The score from 0 to < 50% denoted full dependent, 50 < 75 % score was partially

dependent while score from 75 ≤ 100% considered independent.

Part II: Child quality of life inventory version 4.0: (The Peds QL4.0 generic core scale) which developed by (*Varni, 2014*), to assess health related quality of life of children with CP. This scale was 23 items: **(8 items) for Physical functioning, (5 items) for Emotional functioning, (5 items) for Social functioning and (5 items) for School functioning.**

The sum of the 4 scales is the total score. Each item has a score ranging from 0 – 4. Where, **4=** it is never a problem, **3=** it is almost never a problem, **2 =** it is sometimes a problem, **1=** it is often a problem and **0=** it is almost always a problem.

After that the items are reverse scored and linearly transformed as 0 = 100, 1 = 75, 2 = 50, 3 = 25 and 4 = 0. So that the higher scores indicate better health. Quality of life is classified accordingly into;

Low QOL: <60% of total score

Moderate QOL: 60–75% of total score

High QOL: >75% of total score

Part (III) Family empowerment scale:

The scale was designed by **Koren, et al., (1992)**, and used to ask about three areas of life:

- **About family: Which consisted of (12 items) such** as I feel my family life is under control, I am able to get information to help me better understand my child, I believe I can solve problems with my child when they happen, When I need help with problems in my family...etc.

- **About child's services: Which consisted of (12 items)). such as** I feel that I have a right to approve all services my child receives, When necessary, I take the initiative in looking for services for my child and family, I have a good understanding of the services system that my child is involved in and Professionals should ask me what services I want for my child...etc.
- **About involvement in the community: Which consisted of (10 items) such as** I tell people in agencies and government how services for children can be improved, I know how to get agency administrators or legislators to listen to me, I know what the rights of parents and children are under the special education laws and I feel that my knowledge and experience as a parent can be used to improve services for children and families... etc.

Scoring system:

The sum of the 3 scales is the total score. Each item has a score ranging from 1 – 5. Where, Never = 1, Seldom = 2, Sometimes = 3, Often = 4 and Very often = 5. The items are scored in the same direction and no item scores are reversed, and a higher score indicates relatively more empowerment in each respective area.

Empowerment program:

The researchers plan and implement empowerment program based on actual needs assessment of the studied sample (caregivers and their children). Each mother was assessed twice pre/post

implementation of empowerment program using the previously mentioned tools.

Pilot study:

Before starting data collection, pilot study performed on 10% of caregivers and their CP child randomly from previously mentioned settings, to estimate the time for completing the tools and examination questions' clarity, applicability and relevance. Necessary modifications were finished; these caregivers and their children were excluded from the main study sample.

Validity and Reliability

Face and content validity were achieved through five experts; three professors from the Pediatric nursing and two from Community Health nursing. All experts were affiliated to Ain Shams University, Egypt who reviewed the tools for content accuracy. The developed tools were tested for reliability by using the Cronbach's alpha which detected excellent internal consistency with score (0.987).

Ethical Considerations

The necessary approval from the Ain-Shams University hospitals director through official letter from the Dean of Faculty of Nursing, El-Fayoum University. An informed verbal consent from subjects after explaining the aim of study to participate in the current study. Ensure that the collected data used only for research and maintain complete confidentiality and privacy. Researchers informed the subjects that allow withdraw from the study at any time.

Field work:

The data collection process done over 6 months started from June 2020 till end of November 2020. Data collected two days per week during the morning shift at Sunday and Wednesday. The empowerment program consumed 24 weeks (2 days per week). The sessions of empowerment program started after collection of questionnaire and reported caregivers practice as well as quality of life and empowerment scales to all subjects of the study. The researchers provided empowerment program sessions for caregivers regarding to care of their children with cerebral palsy through use of several teaching aids such as group discussion, question and answer, role-playing, brain storming, demonstration and re-demonstration as well as distribution of explanatory related booklet at the beginning of sessions.

Empowerment program is applied through four stages:**First stage(knowledge enhancement):**

The researchers explained the theoretical knowledge for caregivers about CP such as meaning, etiology, treatment, diet, disease complications and prognosis.

Second stage (self-efficacy enhancement):

The researchers demonstrated the practical skills for mothers such as hygienic care (hand wash, eye care, and oral care), range of motion exercise and breathing & coughing exercise.

Third stage (self-esteem enhancement through participatory training): the researchers asked the mothers to write

down their questions concerning what would be learned from the researchers to be discussed in the next session. Three weeks after holding the last session, the researcher called the subjects to evaluate skills and to be assured about application of the presented materials.

Fourth stage (evaluation): The researchers evaluate the mother's knowledge at the beginning of each session. The researchers ask the children to demonstrate two learned skills appropriately to evaluate their Self-efficacy, while self-esteem was assessed by the level of the mother's cooperation in the participatory training

Statistical Analysis:

Data collected from the subjects were revised, coded and entered through PC. Computerized data entry and statistical analysis were achieved by using SPSS program, version 24. Collected data were offered through using descriptive statistics in the form of frequencies and percentages. T test compares the means of two groups.

Results:**Table (1):** Distributions of the studied children regarding their characteristics (N= 75).

Items	No	%
<u>Child age (year)</u>		
1- <3	19	25.3
3- < 6	25	33.3
6-12	31	41.4
Mean \pm SD 7.3 \pm3.4 years		
<u>Gender</u>		
Male.	35	46.7
Female.	40	53.3
<u>Child rank</u>		
Frist.	37	49.3
Middle.	22	29.3
Last.	16	21.4
<u>Education</u>		
Below age	40	53.3
Primary school.	19	25.3
Preparatory	3	4
None.	13	17.4
<u>Number of sibling</u>		
1	19	25.3
2	40	53.3
3+.	16	21.4
<u>Follow special education</u>		
Yes.	19	25.3
No	56	74.7

Table (1) revealed that mean age was 7.3 \pm 3.4 years, 53.3% of them were females and 49.3% of them ranked as first child. Related to educational level, 25.3% of studied children were at primary school. According to number of sibling, this table showed that 53.3% of them had two siblings. Also, 25.3% of studied children followed special education

Table (2): Distributions of the studied caregivers of CP children regarding their characteristics (N= 75).

Items	No	%
<u>Caregivers age:</u>		
<30	24	32
30 < 40	28	37.3
40+.	23	30.7
Mean SD 33.73±5.6		
<u>Care provider to child</u>		
Mother.	43	57.3
Father.	18	24
Grandparent.	9	12
Sibling/Uncle	5	6.7
<u>Education</u>		
Illiterate	16	21.3
Read/writ	25	33.3
Basic/secondary	21	28
University.	13	17.4
<u>Occupation</u>		
Working.	27	36
Doesn't work.	48	64
<u>Family income LE/month</u>		
Sufficient	15	20
No insufficient.	60	80

Table (2) detected that, mean age of the studied caregivers was 33.73±5.6 years, 57.3% of them were mothers of children. Related to education level, 33.3% of the studied caregivers were able to read and write. According to occupation level, 64% of the studied caregivers were doesn't work. Regarding, family income, 80% of the studied caregiver had insufficient income.

Table (3): The statistical differences of reported satisfactory knowledge and practices score toward care of child with CP among caregivers throughout program stages (pre/post test) (N=75).

Items	Program stages				X ² Test	(p-value)
	Pre		Post			
	No	%	No	%		
Total knowledge	19	25.3	71	94.7	16.899	.000**
Total practice	10	13.3	68	90.7	17.403	.000**

(**) Highly significant at P<0.01

Table (3) demonstrated that, slight more than one quarter (25.3%) of the studied caregivers had satisfactory knowledge at preprogram, while the majority (94.7%) of them improved post program. Related to total practice, less than one fifth (13.3%) of studied caregivers had satisfactory practice pre program compared

to the majority (90.7%) of them post program with high statistical significant difference pre and post program at (p value <0.01).

Table (4): The statistical differences of studied children according to independent level toward activity of daily living as reported practices by caregivers throughout program phases (pre/post test) (N=75).

Items	Program phases				X ² Test	(p-value)
	Pre		Post			
	No	%	No	%		
Feeding						
Dependent	57	76	25	33.3	.745	<0.001**
Partial dependent	15	20	23	30.7		
Independent	3	4	27	36		
Mobilization						
Dependent	59	78.7	13	17.3	13.844	<0.001**
Partial dependent	13	17.3	29	38.7		
Independent	3	4	33	44		
Walking						
Dependent	54	72	22	29.3	10.996	<0.001**
Partial dependent	17	22.7	34	45.3		
Independent	4	5.3	19	25.4		
Dressing						
Dependent	53	70.7	28	37.3	14.275	<0.001**
Partial dependent	20	26.7	32	42.7		
Independent	2	2.6	15	20		
Hygienic measures						
Dependent	55	73.3	21	28	13.654	<0.001**
Partial dependent	16	21.3	30	40		
Independent	4	5.4	24	32		
Elimination						
Dependent	54	72	12	16	15.002	<0.001**
Partial dependent	16	21.3	32	42.7		
Independent	5	6.7	31	41.3		
Communication						
Dependent	49	65.3	10	13.3	16.377	<0.001**
Partial dependent	17	22.7	42	56		
Independent	9	12	23	30.7		
Total activities						
Dependent	19	25.3	7	9.3	18.709	<0.001**
Partial dependent	56	74.7	30	40		
Independent	0	0.0	38	50.7		

(**) Highly significant at $P < 0.001$

Table (4) detected that there was high significant difference between feeding, mobilization, walking, dressing, hygiene measures, elimination and communication

pre and post program with p value <0.01 . Also, less than three quarters (74.7%) of the studied children were partial dependent at total activities, while more than half (50.7%) of them were independent, post program with p value <0.01 .

Table (5): Statistical differences of the studied CP children according to quality of life domains mean scores as reported by caregivers (pre/post test) $n=75$

Quality of life domains	Pre- intervention		Post- intervention		t-value	p-value
	Mean	SD	Mean	SD		
Physical Functioning	15.89	1.59	17.601	2.89	5.613	0.045*
Emotional Functioning	12.66	0.99	16.112	1.30	6.562	0.031 *
Social Functioning	12.48	1.60	15.994	1.60	5.166	0.047*
School Functioning	12.79	1.39	12.93	1.58	2.164	0.064
Total	43.96	4.31	62.637	5.66	8.633	0.008**

Table (5) revealed that, there was slight significant difference related to physical, emotional and social function, pre and post program at (p value <0.05). But, there was no significant difference between mean score, pre and post program related to school function with (p value >0.05). Meanwhile, related to total quality of life, there was high significant difference between mean scores, pre and post program at (p value <0.01).

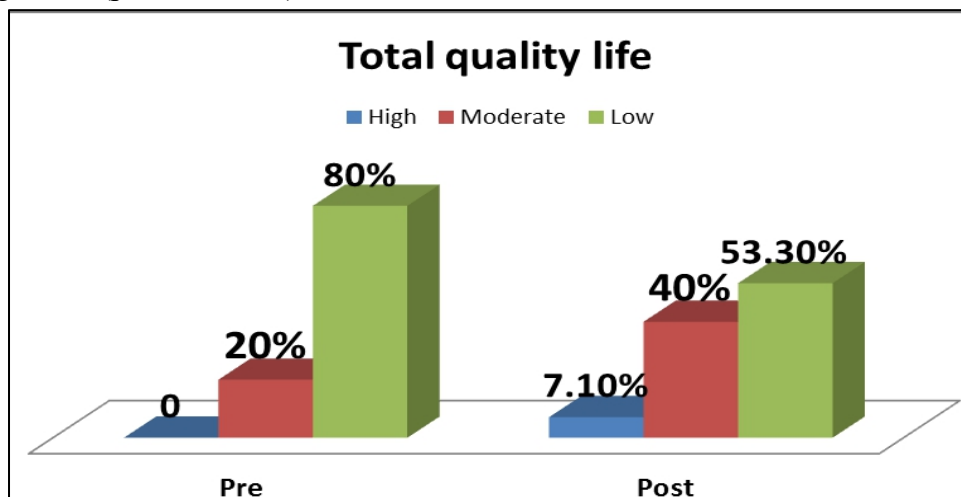


Figure (1): Distribution of the studied CP children according to quality of life domains mean scores (pre/post intervention) $n=75$

Figure (1) revealed that the majority (80%) of studied caregivers had low quality of life, preprogram, compared to 40% of them had moderate quality of life and 7.1% of them had high level post program.

Table (6): Statistical differences of the studied caregivers regarding family empowerment levels (pre/post program) (n=75).

Family empowerment levels	Pre		Post		t-value	p-value
	Mean	SD	Mean	SD		
Family level	17.420	3.92	24.36	2.91	12.634	.003**
Child's services level	22.031	3.94	29.41	4.10	10.547	.004**
Community/political participation level	15.694	4.06	20.62	3.96	9.163	.006**
Total	55.14	6.8	74.39	7.94	13.478	.002**

Table (6) demonstrated that, there was high significant difference related to family level, child's services level and community participation level, pre and post program at (p value <0.01). Related to total family empowerment, there was high significant difference, pre and post program at (p value <0.01).

Discussion

Cerebral palsy considered a compound chronic disease which may affect all age groups over – world. There is no incidence variation between developing and developed countries. Therefore, self – care difficulties, behavioral burden, functional restrictions, seizures, sensory, cognitive, emotional and social impairments and problems of daily living activities may disturb health related quality of life in children suffered from cerebral palsy. So, it is significant to evaluate health related quality of life for CP children and their caregivers (Menlah, et al., 2020).

Regarding the characteristics, the present results stated that, mean age of the studied caregivers was 33.73±5.6 years; more than half of them were mothers of children. In relation to education level, one third of the studied caregivers were able to read and write.

According to occupation level, about two thirds of caregivers were doesn't work. Regarding to family income, more three quarters of studied caregiver had insufficient income. These results supported by the study conducted by *Maggioni and Araújo, 2020* who reported that, more than one third of studied caregivers ranged age between 29-39 years and majority of them were mothers of children. Also, this was supported by the study performed by *Donkor, et al., (2019)* who stated that, more than half of caregivers were unemployed and majority of them were the mothers' children.

As regard characteristics of studied children, the present results stated that, mean age of the studied children was 7.3 ±3.4 years; half of them were females. In relation to educational level, one quarter of studied children were at primary school. According to number of siblings half of them had two siblings. Also, one

quarter of studied children followed special education. These results similar to the study conducted by *Almutairi, et al., (2019)* who reported that, mean age of studied CP children was 9.44 years, SD = 1.66. But, not in agreement with the study conducted by *Polack, et al., (2018)* who detected that mean age was 3 years and 9 months; and more than half of studied children were males.

According to total knowledge and practices of caregivers, the current study detected that, one quarter of studied caregivers had satisfactory knowledge pre-program, while the majority of them had improved knowledge level post program. As regards total practices, less than one fifth of studied caregivers had satisfactory practices preprogram, while the majority of them improved their practice level post program, with high significant difference pre and post program at (p value <0.01). These results confirmed research hypothesis of the study also, may due to effective program training, using illustrative methods during program session, using simple ways to communicate and prepared educational program material dependent on pretest defect. These results were similar with the study conducted by *Hashem and Aziz, 2018* who reported that, the majority of the studied caregivers had unsatisfactory knowledge pre intervention while, all caregivers had satisfactory knowledge related CP and care of associated problems post intervention. Also, this was supported by the study of *Baraka, et al., (2019)* who detected that, the total scores of all of them were poor before educational program while, immediately after educational program the total scores for nearly two thirds of mothers were fair

and more than one third of them were good.

Regarding to daily living practices of CP children, the present results detected that, there was high significant difference between feeding, mobilization, walking, dressing, hygiene measures, elimination and communication pre and post program at (p value <0.01). Also, revealed that around three quarters of studied children were partial dependent at total activities, while half of studied children were independent post program, with (p value <0.01), these results proved research hypothesis of the study who supposed that, improving knowledge and practices of caregivers had positive effect on the daily activity of children. These results were in accordance with the study performed by *Mutoh, et al., (2019)*, who stated that, hippo therapy was linked with improved cadence, step length, mean acceleration; stabilized displacement of patients; and positive relationship between the psychological status and QOL of the caregivers than those seen in the control group ($p < 0.05$). Also, consistent with the study done by *Chang, et al., (2019)* and *Akhter, et al., (2018)* who reported that, trained caregivers had positive effect on daily living skills of CP children and improvement of hygiene measures related to oral care.

As regard quality of life of CP children, the current study revealed that, there was slight significant difference related to physical, emotional and social function pre and post program with (p value <0.05). But, there was no significant difference between mean score at pre and post program related school function at p value >0.05 . Meanwhile, regarding total quality of life,

there was high significant difference between mean scores pre and post program with (p value <0.01). These results may due to school function needed long term intervention and multi team work at school and at home, while empowerment program for family may improve relation between family and child which improve emotional function. These results were in accordance with the study performed by *Nobakht, et al., (2020)* who demonstrated that, the mean scores of total QOL scores post-intervention in the study group were higher than the control group. Also, this was in agreement with the study by *Parisi, et al., (2016)* who reported that, providing parents with cognitive and behavioral strategies may have the possible to enhance caregiver health outcomes. Also, this was supported by the study by *Koltuniuk, et al., (2019)* who demonstrated that, Cerebral palsy has a negative impact on the quality of life and family functioning and the QOL of children with CP is reduced compared to the QOL of healthy children and their condition has a significant impact on family functioning. And, these results were the same with *Makris, et al., (2019)* who showed that, Physical quality of life is, invariably, more affected in those with cerebral palsy. The association between cerebral palsy and psychosocial quality of life is less clear.

Regarding empowerment program for studied caregivers' mothers, the current study demonstrated that, there was high significant difference related to family level, child's services level and community participation level pre and post program at (p value <0.01). Regarding to total family empowerment, there was high significant difference pre

and post program at (p value <0.01). These results may due to knowledge about parental empowerment in different contexts and links with child's characteristics and family and the services they receive can contribute to additional reinforcing family empowerment and identifying parents in need of extra support. These results supported with the study performed by *Kallesson, et al., (2020)* and *Bunning, et al., (2020)* who reported that, training program for families of CP children improving level of empowerment of caregivers.

Conclusion

According to the findings and research hypothesis, the study can concluded that more than three quarters of the studied caregivers reported that their children with CP had low quality of life pre empowerment program, while post empowerment program, more than one third of them reported that their children with CP had moderate quality life. Meanwhile, in relation to total quality of life, there was high significant difference between mean scores pre and post empowerment program at (p value <0.01). At the end, empowerment program for caregivers had positive effect on quality life of CP children.

Recommendation

- Preparing continuous empowerment program for caregivers of children suffered from CP.
- Further researches about quality of life of children with CP with increasing sample size at different settings.

- Provision the guideline booklet to all newly admitted children with CP in all neurological outpatient clinic and rehabilitation center to help them in improving their knowledge and practices by needed information.

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