

Effect of Educational Intervention Program on Mothers' Knowledge and Practice about Quality of Life for Their Children with Cerebral Palsy

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Abstract :Background: Cerebral palsy is one of the most common chronic motor disabilities that have a negative impact on the quality of life of children and their families.

Aim of this study was to determine the effect of educational intervention program on mothers' knowledge and practice about quality of life for their children with cerebral palsy.

Subjects and Method: A quasi-experimental research design was used for sixty mothers and their children with cerebral palsy at Pediatric Neurology Unit of Tanta University Hospital. Three tools were used to collect the required data:

Structured Interview schedule to collect sociodemographic data and medical history of mothers and their children and mothers' knowledge about cerebral palsy,

Mothers' Care Reporting Sheet and Cerebral Palsy Quality of Life Questionnaire for Children. Results: The total scores of mothers' knowledge for most of them (88.3%) were poor before educational program while, all of them (100%) immediately and nearly three quarters (71.67%) after one month of program implementation obtained good scores. Regarding to mothers' reported care, The total scores of all of them (100%) were poor before educational program while, immediately after educational program the total scores for nearly two thirds of mothers (61.67%) were fair and more than one thirds of them (38.3%) were good. Quality of life for nearly three quarters of children (73.33 %) were poor before educational program while, the majority (95%) and most of them (88.33%) had fair scores immediately and after one month respectively.

Conclusion: There was a significant improvement of mothers' knowledge and reported care provided to their children with cerebral palsy as well as children quality of life

Recommendations: Continuous health education program should be applied to mothers of children with cerebral palsy in health facilities to improve their knowledge and practice that affect children quality of life.

Keywords: Cerebral palsy, Quality of life.

Date of Submission: 05-03-2019

Date of acceptance:22-03-2019

I. Introduction

Children with cerebral palsy (CP) have physical, learning disability, social and behavioral difficulties that require specialized services and intensive care. Cerebral palsy has been recognized by John Little who attempted to define CP in 1853. Cerebral palsy is one of the most common disorders that affect movement and posture development due to non-progressive disturbances of the brain occurred before, during or after infant birth^(1, 2).

Cerebral palsy is occurring in approximately 2-2.5 of 1000 live births globally. It has been found that, 80% of the global prevalence of CP is in low resources countries that having larger populations. Cerebral palsy represents 67% of the severe motor disabilities in childhood. Research reported that the overall prevalence rates have no substantial changes for the birth year periods of 1985 to 2010^(3,4). Although some risk factors have been identified, including placental abnormalities, birth asphyxia, and neonatal medical problems, the etiology of CP is not well understood⁽⁵⁾.

Children with CP have several associated health problems such as, intellectual, communicative and sensory impairments, speech disturbance, epilepsy, dental and nutritional problems. Therefore, management of children with CP requires a multidisciplinary and coordinated approach to achieve child's independence and community participation⁽⁶⁾

Families of children with cerebral palsy facing emotional, social and financial challenges that affect their children quality of life (QOL) negatively ⁽⁷⁾. The concept of QOL is subjective and multidimensional that includes the functional capacity and psychosocial interaction between the child and its family. Cerebral Palsy QOL includes children social well-being and acceptance, functioning, participation and physical health, emotional well-being, access to services, pain and impact of disability, and family health ^(8,9).

II. Aim of the study

Determine the effect of educational intervention program on mothers, knowledge and practice about quality of life for their children with cerebral palsy.

III. Subjects and Method

3.1 Study design: A quasi-experimental research design was used in the present study.

3.2 Study hypotheses: Educational intervention program is expected to improve mothers' knowledge and practice about quality of life for their children with cerebral palsy.

3.3 Study setting: This study was conducted at Pediatric Neurology Unit of Tanta University Hospital

3.4 Subjects: A convenient sample of sixty mothers and their children with cerebral palsy were included.

3.5 Tools of the study: Three tools were used for data collection

Tool (I): Structured Interview Schedule: it was constructed by the researcher after reviewing the related literature and includes three parts:

Part I: Socio-demographic Characteristics of: a- Mothers such as: age, level of education, occupation, residence and consanguinity. b- Children such as: age, sex, birth order and number of siblings.

Part II: Past and Present Medical History related to a- Mothers such as: any health problems during prenatal, perinatal, postnatal period and presence of any chronic disease. b-Past and present medical history of children.

C-Associated Health Problems of Children with Cerebral Palsy: It included any health problems facing children such as: feeding problems, motor, speech, hearing disorders, visual, behaviour abnormalities and learning difficulties.

Part III: Mothers' knowledge about Cerebral Palsy: such as: (definition, causes, signs and symptoms, complications that may occur). This part contained 8 questions. Each question was scored (0, 1, 2 points). Correct and complete answers scored (2), correct and incomplete answers scored (1) and wrong answers or not answered questions scored (zero). The sum of all questions was 16. **The total scores of mothers' knowledge** were calculated and classified as follows: < 50 % was considered poor knowledge; 50-75 % was considered fair knowledge and > 75 % was considered good knowledge.

Tool II: Mothers' Care Reporting Sheet: It was constructed by the researcher after reviewing the related literature to assess mother's care provided to their children (care of motor disorders, drooling care, dental care, speech improvement, care of seizure, hearing, visual, pain and sleep problems). Mothers' reported care consisted of 11 items. Each item was scored (2) for correct and complete reported care, (1) score for correct incomplete care and (zero) for wrong care. The sum of total items was 22. **The total scores of mothers reporting care:** were calculated and classified as: < 50 % was considered poor care; 50-75 % was considered fair care and > 75 % was considered good care.

Tool III: Cerebral Palsy Quality Of Life Questionnaire for Children (CPQOL- Child).

It was developed by international multidisciplinary team of clinical and child health researcher, with collaboration with the parents and children with cerebral palsy ⁽²⁰⁾. It was adapted by the researcher to assess children quality of life. The researcher used Parent-proxy version of CPQOL- Child (for parents of children aged 4-12 years). The CP QOL-Child measured the following seven areas of a child's life:

Social wellbeing and acceptance, participation and physical health, feelings about functioning, emotional wellbeing and self-esteem, pain and impact of disability, access to services and family health. Children's quality of life consisted of 32 items. Each question was scored (0, 1,2,3,4 grades). Zero for no problem, (1) for almost never a problem, (2) for sometimes a problem, (3) for often a problem, and (4) for almost always a problem. The sum of all questions was 128.

Children's quality of life was categorized into three categories: Good quality of life when the total scores ranged from 0 to less than 43. Fair quality of life when the total scores ranged from 43 to less than 86. Poor quality of life when the total scores ranged from 86 up to 128.

Method

1- Administrative process:

An official permission was obtained from Faculty of Nursing, Tanta University directed to administrators of Pediatric Neurology Unit of Tanta University Hospital to obtain their approval and cooperation for carrying out this study.

2- Ethical and legal considerations:

Mothers were informed about the confidentiality of the information and the nature of the study not cause any harm or pain to their children. Mothers were assured that the data collected were used only for the purpose of the study. Oral consents of mothers were obtained to participate in the study after explaining the aim of the study.

3- Developing the tools

Three tools were developed by the researcher based on the review of related literature. Five experts in pediatrics and pediatric nursing field tested the face and the content validity (94%)

4- A pilot study was conducted on 10 % of study sample to test clarity, reliability, visibility and applicability of the study tools. The necessary modifications were done accordingly. The Pilot study was excluded from the study sample (Cronbach's Alpha which was 0.894).

5- Data collection procedure: was compromised through three phases:

I-Assessment Phase:

It was carried out by the researcher for all study subjects to collect baseline data. The researcher was available 6 days per week to assess mothers' knowledge about cerebral palsy using **Tool I**.

- Mothers' reported care provided to their children was assessed before, immediate and after one month after application of educational program using **Tool II**.

- Quality of life for their children was assessed before, immediate and after one month of application of educational program using **Tool III**.

- Mothers and their children were interviewed individually or in the group to fill the questionnaire sheet.

- The average time needed for each mother ranged from 10- 15 minutes. (Nearly 2sheets/ day)

2- Implementation Phase included:

- Setting objectives.

- Preparation of the content which was covered the reasons behind the application of the session.

- The educational program was conducted in the Pediatric Neurology Unit at morning shift through four sessions.

- Two sessions were conducted daily for constructive 2 days.

- Time of each session was ranged from 30-45 minutes.

- At the beginning of the first session, mothers were oriented about the educational program content, purpose, and its effect on their children health status.

-Each session was started by a summary about what has been discussed in the previous session and the objectives of the current session, using simple Arabic language and different teaching media (lectures, demonstration, group discussion and using audiovisual material) to facilitate their understanding.

-The sessions covered the following topics:

The first session: about (definition of cerebral palsy, causes, risk factors and types).

The second session: focused on (manifestations of cerebral palsy, complication and importance of compliance to drugs).

The third session: related to (management of cerebral palsy, physiotherapy, importance of speech therapy and communication

The fourth session: consisted of care of seizure if present, daily care and coping strategies with cerebral palsy.

-Each session ended by a summary of its content and feedback from the mothers was obtained to ensure that mothers got the maximum benefit.

3-Evaluation phase:

The Effects of the educational intervention program on mothers, knowledge, and practice and children quality of life were done through comparing the pretest and posttest. This phase was done three times before, immediately and one month after the program implementation.

Statistical analysis:

The collected data were organized, tabulated and statistically analyzed using (Statistical Package for the Social Science, (version 20, spss Inc., Chicago II, USA). For qualitative data, comparison between two groups was done using Chi- Square testing (X^2). For quantitative data, the range, mean and standard deviation were used. Comparison between more than two means of parametric data, the F value of analysis of variance (ANOVA) test was calculated where scheffe test was performed to compare between each more than two means.

Correlation between variables was evaluated using Pearson's correlation coefficient (r). Significance was adopted at (p <0.05) for interpretation of results of tests of significance

IV. Results

Table (1) demonstrates percentage distribution of sociodemographic characteristics of studied mothers. It was observed that, the age of mothers was ranged from 22-53 years with the mean of (32.792±6.666). In relation to the level of education, it was evident that, 41.6 of mothers read and write while, 23.33% of them had secondary education, 18.3 % completed their university education and the rest of them 16.6 % were illiterate. According to their job, it was found that, the majority of mothers (90%) not working and only 10% working. Two thirds of the working mothers (66.6 %) left their children under the care of their fathers or other family members. Most of mothers (85%) were from rural areas. The study revealed that, more than two thirds of mothers (68.3%) had no consanguinity while 31.6% had consanguinity and (57.8 %) were 2nd cousin.

Table (2) clarifies the percentage distribution of sociodemographic characteristics of studied children. It was observed that, the age of children was ranged from 4-12 years with the mean of (5.975±2.286). More than half of them (55 %) were males and 36.6 % were the first children in the family and 43.3% had two siblings.

Table (3) shows percentage distribution of studied children according to their previous medical history. It was observed that, more than three quarters of the studied children (78.3 %) didn't have premature labor. Most children (85.3%) had asphyxia and 43.9% difficult labor. The table also shows that 45% of children didn't have any problems after delivery or during the first three years of life while 39.3% had fits after delivery. In relation to the reason for hospital admission, it was found that, more than three quarters (78.2 %) admitted to hospital because of pneumonia.

Figure (1) presents percentage distribution of studied children according to their associated health problems. It was observed that, most children (88.3%) had eating difficulties followed by communication disorders 78.3%, visual disability 53.3%, epilepsy 38.3% and hearing disability 3.3%.

Figure (2) illustrates total scores of mothers' knowledge about cerebral palsy. It was observed 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).

Figure (3) demonstrates total scores of mothers reported care provided to their children. It was observed that, before educational program all of them (100 %) provide poor care while, nearly two thirds (61.67%) provide fair care and 38.3% provide good care immediately after educational program and most of them (80.00%) provide fair care after one month. There were statistically significant differences during three phases of educational program before-immediate , before –one month after and immediate – one month after (p<0.001, p<0.001 and p = 0.002) respectively.

Figure (4) presents total scores of children quality of life. It was observed that, before educational program nearly three quarters of children (73.33 %) had poor quality of life while, the majority of them (95%) had fair quality of life immediately and most of them (88.33%) one month after educational program implementation. There were statistically significant differences between before -immediately after and before – one month later (p<0.001). On the other hand, no statistically significant difference regarding children quality of life immediately and one month after educational program (p=0.245).

Table (1): Percentage Distribution of sociodemographic characteristics of Studied Mothers

The Studied Mothers (n=60)		No	Sociodemographic Characteristics of Mothers
%			
22-53			Age in (years) Range Mean ±SD
32.792±6.666			
16.67	10		Educational level Illiterate
41.67	25		Read and write
23.33	14		Secondary education
18.33	11		High education
10.00	6		Mothers' Job Working
90.00	54		Not working
			Caregiver During Work

66.67 33.33	4 2	Father or family member Relatives
85.00 15.00	51 9	Residence Rural Urban
31.67 68.33	19 41	Consanguinity Yes No
26.32 57.89 15.79	5 11 3	The degree of consanguinity 1 st cousin 2 nd cousin Far distance

Table (2): Percentage Distribution of Sociodemographic characteristics of Studied Children.

The Studied Children (n=60)		Sociodemographic characteristics of Children
%	No	
		Age in (years)
4-12 5.975±2.286		Range Mean ±SD
55.00 45.00	33 27	Sex Male Female
36.67 33.33 10.00 20.00	22 20 6 12	Birth Order First Second Third More third
10.00 25.00 43.33 16.67 5.00	6 15 26 10 3	Number of siblings No One Two Three Four or more

Table (3): Percentage Distribution of Studied Children According to Their Previous Medical History

The Studied Children (n=60)		Previous Medical History of Children
%	No	
21.67 78.33	13 47	premature labor Yes No
31.67 85.36 4.87 43.90 7.31 7.31	19 35 2 18 3 3	*Delivery Problems No problems Asphyxia Birth Trauma Difficult labor Low birth weight Hydrocephalus
45.00 27.27 6.06 39.39 24.24 21.21	27 9 2 13 8 7	* Post-delivery Problems No problems Encephalitis brain hemorrhage Fits Jaundice Respiratory distress
13.04 78.26 32.60 4.34 17.39 8.69 7.31	6 36 15 2 8 4 3	* Reasons for hospital admission Surgery Pneumonia Fits Brain hemorrhage Jaundice Dehydration Respiratory distress

*More than one answer is allowed

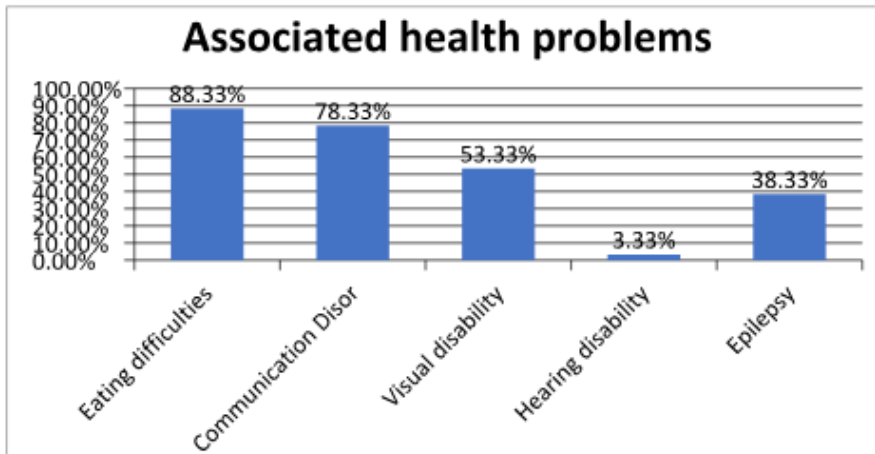


Figure (1) shows Percentage distribution of Studied Children According to Their Associated Health Problems with Cerebral Palsy

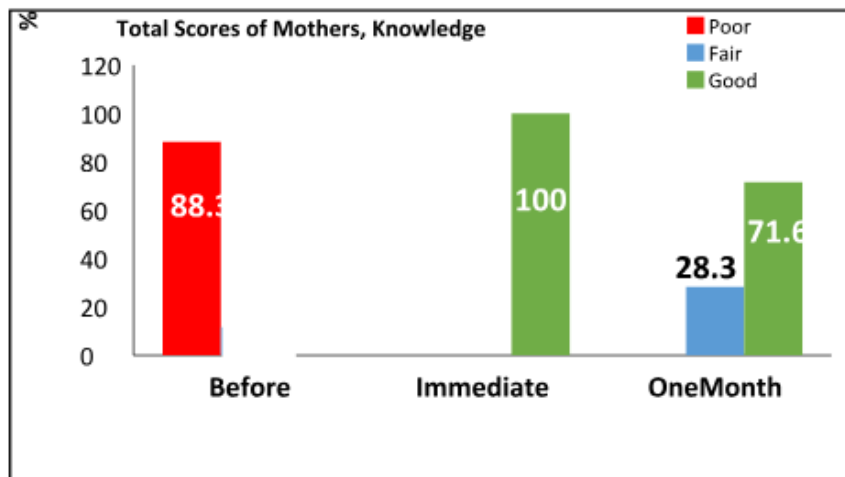


Figure (2): Total Scores of Mothers' Knowledge about Cerebral Palsy before, immediate and after one month.

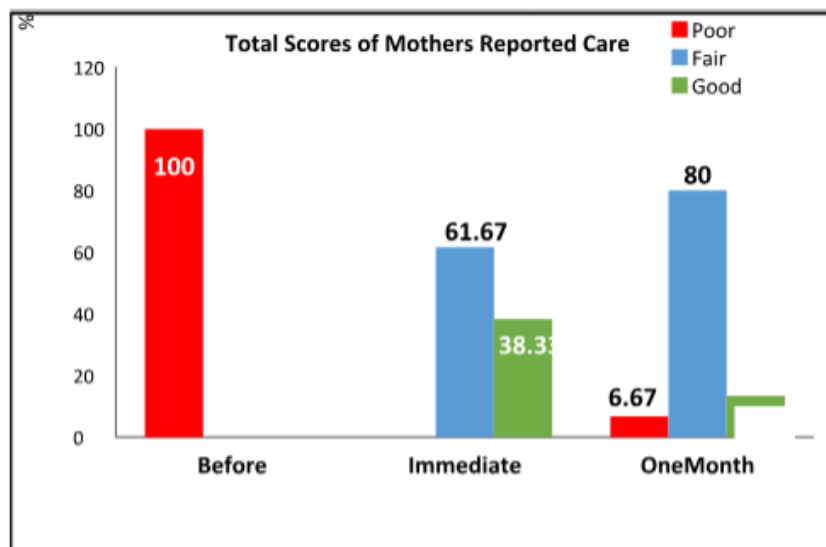


Figure (3): Total Scores of Mothers Reported Care to Their Children with Cerebral Palsy before, immediate and after one month.

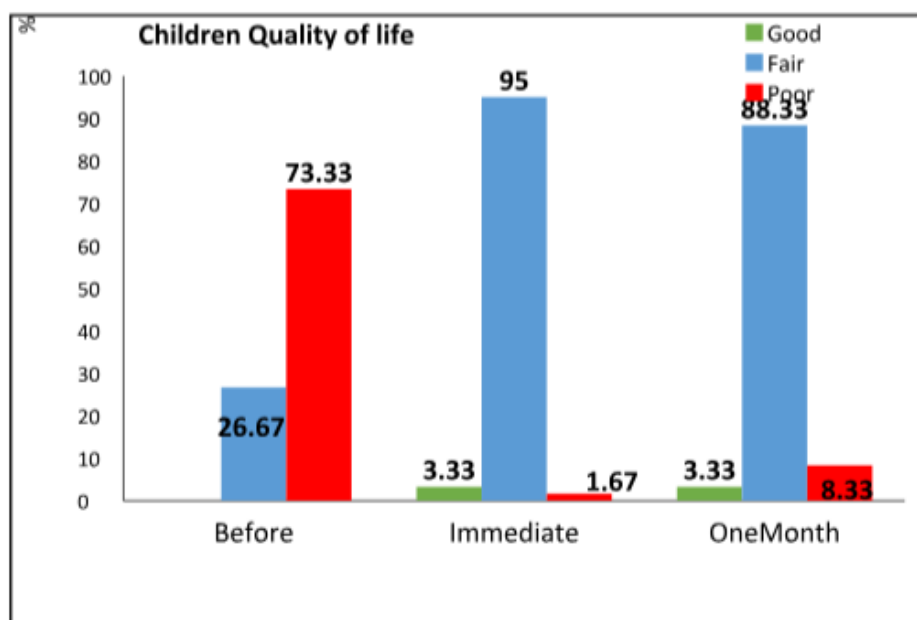


Figure (4): Total Scores of Quality of life of Studied Children

Table (4): Correlation between Mothers, knowledge, Reported Care and their children quality of life

Correlations					
Time		Knowledge		Reported Care	
		R	P-value	r	P-value
Before program	Reported Care	0.452	<0.001*		
	Quality of life	0.021	0.873	-0.025	0.849
Immediately after program	Reported Care	0.314	0.015*		
	Quality of life	-0.092	0.486	0.373	0.003*
One month after program	Reported Care	0.483	<0.001*		
	Quality of life	0.037	0.777	0.373	0.003*

V. Discussion

Cerebral palsy is the most common chronic motor disability and neurological disorders occurred by injury of the brain before, during and after birth. This disease is usually accompanied by cognitive, communicative, sensory, behavioral, epileptic and muscular-skeletal problems which limit the children participation in social activities⁽¹⁰⁾.

The primary goal of CP management is to help children and their families to live healthy and productive life. Continuous educational program to caregivers and regular follow up play an important role in improving quality of life of children with CP and their families, improving the growth and development, reinforcing teaching regarding special feeding programs, safety environment, immunizations, vision, hearing and dental screenings and use of adaptive devices. Caregivers who know their family special needs are in the best position to provide support and guidance⁽¹¹⁾.

The study revealed that most of mothers and their children were from rural areas. This may be due to low socioeconomic status in rural areas, poor antenatal care, inadequate health care facilities, and high level of illiteracy in rural areas. The study was in agreement with **Tseng et al (2018)**⁽¹²⁾, who reported that a higher incidence of CP is associated with low income and rural residential location. Similarly, **Abd Allah and El Awady (2012)**⁽¹³⁾ who found that more than two-thirds of cerebral palsy children were living in rural areas.

As regards the relationship between consanguinity and occurrence of CP, The study revealed that, more than two thirds of mothers had no consanguinity. This finding could be explained that, consanguinity is not the main contributing factor for occurrence of CP due to increase awareness about problems associated with consanguineous marriages especially with familial history of neurological disorders and decreasing incidence of consanguineous marriages in many areas in Egypt.

This finding was incongruent with **Abdul Hai and Sarker** ⁽¹⁴⁾ (2015) who stated that there were more than 2.5 times more chance of developing CP among the parents who had positive consanguinity.

The study revealed that, more than half of studied children were males. This may be due to Recessive X-linked chromosome variants may contribute to this difference and males may be more vulnerable to genetic mutation (point or copy number) than females.

The findings were in agreement with **Yasin and Abd-Elazem** (2016) ⁽¹⁵⁾ who reported that the prevalence of CP was higher among boys than girls in Bani Mazar ,Minya .Similarly **Tseng** (2018) ⁽¹²⁾ who found that, a higher prevalence of CP is associated with male sex. The finding was incongruent with **EL-Tallawy et al** (2011) ⁽¹⁶⁾ ,who stated that the prevalence of CP was higher among girls than boys in El-Kharga District- new Valley (Egypt) due to neglectation of periodic caring for mothers with girls' sex of fetus .

The study revealed that most of the studied children had birth asphyxia and less than half of them had difficult labor. This may be due to birth asphyxia is marked by oxygen loss and blood supply loss which places the infant at a high risk for cerebral hypoxia and acidosis with increased level of carbon dioxide in the bloodstream. This can lead to brain damage and hypoxic ischemic encephalopathy (HIE) which is one of the leading causes of infant mortality or severe neurological impairments after birth such as cerebral palsy.

The current study was in line with **Eyong and Asindi** ⁽¹⁷⁾ (2018) who reported that, the commonest known risk factors for CP were severe birth asphyxia, CNS infections, kernicterus and prematurity. More than half of cases had severe birth asphyxia.This finding was incongruent with **Ellenberg and Nelson** ⁽¹⁸⁾ (2013) who not supports the belief that, birth asphyxia can cause CP and added that the clinical picture of birth asphyxia at birth cannot be specifically identified.

The current study showed that more than three quarters of the children admitted hospital because of pneumonia. This may be due to weakness of breathing and swallowing muscles can cause aspiration or the inhalation of foreign objects lead to aspiration pneumonia. Children with CP are more likely to experience gastro esophageal reflux. When material from the stomach rises up to the esophagus, aspiration can occur. Other causes include insufficient cough, upper airway obstruction and progressive kyphoscoliosis that can restrict the function of the lungs and make breathing more difficult. The lungs may also lose function due to atrophy as children with CP are less active and breathe less deeply.

The finding was in agreement with **Proesmans** ⁽¹⁹⁾ (2016) who reported that, children with neurocognitive impairment often present with chronic or recurrent respiratory problems, which have an important impact on quality of life and life expectancy.

The current study showed that more than three quarters of the studied children had communication disorders. This is due to cerebral palsy characterized by motor disabilities that impair movements needed for vocalization, speech, facial expression and gestures. The finding of this study was in line with **Price** ⁽²⁰⁾ (2013) who stated that, children with cerebral palsy have disorders of social communication skills such as social responsiveness and joint attention.

Regarding presence of visual disability, more than half of the studied children suffered from visual abnormalities. This could be attributed to cerebral palsy caused by damage to different areas of the brain. Bilateral occipital lobe damage can affect processing of vision related to balance and posture as well as coordination of visual skills such as tracking, fixations, and quick eye movements and interfere with binocularity of the eyes leading to visual dysfunction. The findings were in agreement with **Dutton et al.**, ⁽²¹⁾ (2012) who reported that, cerebral palsy is commonly associated with cerebral visual impairment and cause impaired visual guidance of movement.

The current study showed that ,more than one thirds of the studied children had epilepsy .It may be due to brain damage that cause change in electrical activity of the brain leading to seizure .The finding of this study was in line with **Shang et al** (2015) ⁽²²⁾ ,and **Minciu** (2012) ⁽²³⁾ who found that epilepsy occurs in about one half of the cases.

Regarding to mothers' knowledge about CP, the result of the present study revealed that, most of mothers had poor knowledge before educational intervention program. This may be due to low educational level of mothers, poor health facilities in rural areas, as well as insufficient health teaching programs that were provided to families by health facilities and social stigma that some mothers had and can prevent them from asking any question about their children health status. The findings with in agreement with **Karande and Patil** ⁽²⁴⁾ (2008) who found that Parents knowledge about CP are poor and inadequate before educational program.

On the opposite side immediately after implementation of educational program, the total scores of all mothers' knowledge were good. This could be attributed that the content of program was developed based on mothers' and children needs, it's clarity and simplicity, using of audiovisual aids, availability of the researcher in the field for more clarification, using simple language and frequent repetition to fix the knowledge. Similarly, **Arora et al.**, ⁽²⁵⁾ (2014) who stated that, Parents knowledge about CP is inadequate and can be improved by conducting educational programs in special clinics to achieve effective management.

Furthermore, one month after educational program, the total scores of mothers' knowledge were slightly reduced as about three quarters had good scores. This indicates that the improvement in knowledge was partially lost one month after program. This result might be explained by the fact that knowledge retention is usually affected by time. Similarly, **Amer (2010)**⁽²⁶⁾ who found that, after three months of program implementation the mothers' knowledge was decline but still higher than before the program regarding all items about knowledge.

Regarding total scores of mothers' reported care to their children with CP, the results of the current study revealed that, all mothers had poor care before educational program. This could be explained in the light of low educational level of mothers lead to poor knowledge about care, low socioeconomic status of most families which make obstacles for providing complete and effective care and decrease health teaching programs provided to families by health facilities about care of cerebral palsy children.

The result was in agreement with **Amer (2010)**⁽²⁶⁾ who found that mothers' care provided to their children with CP was deficient and all of them provide unsatisfactory care before program. **Similarly, Khalil et al., (2018)**⁽²⁷⁾ stated that there is a wide gap between the actual care provided to children with cerebral palsy and the recommended standards. Moreover, the documentation system in the hospital is poor. A quality improvement plan is needed for the provision of care to children with cerebral palsy.

On the other hand, immediately and one month after program implementation, there was an improvement in mothers' care towards their children with cerebral palsy compared to care before program. This may be due to the new knowledge and skills that mothers acquire from standard educational intervention program that focused on care of associated health problems and the mothers become able to apply it for their children.

The present study was in line with **Mostafa et al., (2015)**⁽²⁸⁾ who reported that frequent health education programs are necessary to improve mothers' adjustments toward care of their CP children.

In relation to the total scores of the studied children quality of life, it was observed that, nearly three quarters of the children had poor quality of life before educational program. This could be attributed to low educational level of mothers, poor maternal knowledge and care before program and many families had low socioeconomic status and sever motor disabilities that impair daily life activities of children. The finding of the present study was incongruent with **Arnaud's and White-Koning (2008)**⁽²⁹⁾ who found that, most severely impaired children (in terms of motor functioning or intellectual ability) do not always have the poorest quality of life.

On the other hand, the majority and most of children had fair quality of life immediately and one month after educational program respectively. This could be explained in the light of the effectiveness of educational intervention program was developed based on mothers' and children needs, and consequently improving mothers' knowledge and skills required for improving children quality of life. The result was in line with **Shrestha's and Poudel (2018)**⁽³⁰⁾ who found that, overall QOL is fairly good in children with CP.

VI. Conclusion

Based on the results of the present study, it can be concluded that there were an improvement in mothers' knowledge, reported care and children quality of life after educational program.

VII. Recommendations

Based on the findings of the present study, the following recommendations are suggested:

- 1-Continuous health education program should be applied to mothers of children with cerebral palsy in health facilities to improve their knowledge and practice that affect children quality of life.
- 2- Advanced in-service training program based on evidence based nursing practice and new trends should be applied regularly for nurses to increase their awareness about effective management of cerebral palsy.

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Nagwa Ibrahim Baraka. " Effect of Educational Intervention Program on Mothers, Knowledge and Practice about Quality of Life for Their Children with Cerebral Palsy" .IOSR Journal of Nursing and Health Science (IOSR-JNHS), vol. 8, no.02 , 2019, pp. 43-52.