An Intervention Program for Mothers Regarding Dependency Level of their Children with Cerebral Palsy

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Abstract

Cerebral palsy (CP) is a permanent disorder of posture and movement resulting from brain damage occurring in the baby or young child. Cerebral palsy is a term used to describe a collection of disorders caused by abnormal brain development or damage to the brain that occurs around the time of birth or early in life. This study aimed to evaluate the intervention program for mothers regarding dependency level of their children with CP. Setting the current data was Neurology out- patient clinic at pediatric hospital Ain Shams University. Sample, The study was conducted on one hundred and twenty four mothers who have been selected for the program pre, post, and after 3 month later. Tools: Two tools for data collection, tool (I) An interviewing questionnaire sheet (II) Child's activities of daily living assessment. Results of this study showed that the main age of mothers was 37.6 ± 0.6 years and noticeable improvement in the mothers' knowledge and practice and dependency level of their children were detected after implementation of intervention program compared to pre and 3 month after program implementation. So, this study concluded that intervention program affected positively regarding caring of mothers regarding dependency level of their children with cerebral palsywhich indicate justification of the study hypotheses. this study recommended that Educational sessions should be provided for mothers of cerebral palsy children about care of their children, as well as, community resources from whom they may seek assistance and support to fulfill with all dependency level of their CP child.

Key words: Cerebral palsy, independency level, practice

Introduction

Cerebral palsy (CP) is a permanent disorder of posture and movement resulting from brain damage occurring in the baby or young child. Cerebral palsy is a term used to describe a collection of disorders caused by abnormal brain development or damage to the brain that occurs around the time of birth or early in life (Sawatzky,2015).

Cerebral palsy is a general term for a group of permanent movement problems that do not get worse over time. They cause physical disability, mainly in the areas of body movement. There may also be problems with sensation, depth perception, and communication ability. Difficulty with cognition and epilepsy are found in about one-third of cases. There are subtypes including a type characterized by spasticity, a type characterized by poor coordination, and

types which feature both symptoms and neither (Gulanick&Myers,2016

CP may be caused by damage to the parts of the brain that control movement, this damage generally occurs during the fetal or perinatal period, particularly in premature infants. Common prenatal causes are separation of the placenta, bleeding, maternal infection nutritional deficiencies mean while perinatal causes are anoxia immediately before, during and after birth, asphyxia, and birth trauma about 10% to 20% occur after birth. Common postnatal causes are head trauma. infection and accident cerebrovascular (Zarei &Gilanian, 2015).

Cerebral palsy is the most common motor disability in childhood. Population-based studies from around the world report prevalence estimates of CP ranging from 1.5 to more than 4 per 1,000 live births or children of a defined age range. In Egypt, there are more than 3.4 million handicapped child. The prevalence of CP in Egypt ranges from 2 to 3 per 1000 live births, this rate increases to 40-100 per 1000 live births among babies born very early or with very low birth-weight The estimation of children with CP in Egypt is about 76.117,46 (WHO,2011)

Mothers of the children with CP are vital member of the professional team; the most important role of them is the lifelong interest in the commitment to their children. They may feel helpless and confused, so that they need information, intervention and support to rehabilitation program and learn to manage the practical difficulties. which disrupt can the developing relationship with their children (Winder, 2013).

Mothers as caregivers may not fulfill their roles due to lack of understanding to the physical,

psychological, emotional, social needs of their child. They like to help themselves and sometimes form own help groups and arrange friendships and events, etc. In general they receive little support from relatives, friends and neighbors (Stenvenson, 2016).

Intervention program may be defined as an organized method of ensuring that people have knowledge and skills for a specific purpose and that they acquired the necessary knowledge to perform the duties of the job. The knowledge may require increased affective, motor, or cognitive skills. It is expected that acquiring new skills will increase productively or create a better product (Shahim, 2014).

The Community health nurse is expected to fill all of her role as care provider, advocate, teacher and Counselor, observer, organizer and decision-maker. 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 (MC-Court, 2015).

Significance of the study:-

Cerebral palsy is damage to the brain that cannot currently be fixed treatment and therapy help manage effects on the body. The injury &damage to the brain is permanent. The brain doesn't heal as other parts of the body. Because of this, the CP itself will not change for better or worse during a person's life time. It is a blanket for several disorders that affect normal, healthy movement (Martin, 2016).

Aim of the study:

The aim of this study was to evaluate the intervention program for mothers regarding dependency level of their children with CP through, assessing level of mothers' knowledge practices related to care for their children with cerebral palsy and the dependency level of the children, Planning, Developing, implementig of educational intervention program, and evaluate the outcome of the intervention program on the level of knowledge, practice related to care and dependency level of the children.

Research Hypotheses

- 1-Mother's level of knowledge and practice related to their children care will be increasing significantly post program.
- 2-Intervention program will improve some factors might affect on level of mother's knowledge and practices also, dependency level of their children.

Subject and Methods:

Research design:

Intervention design will be conducted for this study.

Setting:

The study conducted at the Neurology out- patient clinic at pediatric hospital Ain Shams University

Subjects:

A purposive sample of 124 mothers accompanying their children. in Neurology out- patient clinic at pediatric hospital Ain Shams University.

Tools of data collection:-

1-**First tool**: - An interviewing questionnaire divided into four part:-

Part one:- socio-demographic data of mothers and their children as Age, level of education, occupation Bailey (2011).

Part two:-Child health assessment (using medical record) weight,hight, medical history and investigations. Scoring: Mild: less than 3 problems, Moderate: 3 - 5 problems, Sever: more than 5 problems. These was developed by the researcher based on comprehensive reviewing and recent literature Deon and Gaebler-Spira (2014).

Part three:-It was designed to assess level of mothers' knowledge about CP (pre, post &follow up).**Scoring**: incorrect answer (0 -49%) (**Poor**), correct but incomplete answer (50-69%)**Average** and correct answer (70 -100%) (**Good**).

Part four: It includes assessment of mothers 'practical knowledge regarding their children with CP (pre, post &follow up). Scoring: Not done: (0 -49%), Done but incomplete: (50-69%), Done correctly: (70 -100%) Alber man, (2013).

2-Second tool: - Child's activities of daily living (ADL) assessment. Scoring: 1 - 12 = dependent, 13 - 23 = Assisted (independent with assistant (partial dependent), 24 - 36 = Independent (Shaw, 2010). Preparatory phase:

It includes reviewing of literature related to the program design and the theoretical knowledge of the various aspects of the intervention program using books, articles, magazines, and an internet to develop the tools for data collection.

Pilot study: It was carried out in outpatient clinic for 12 mothers

(10% of study sample). Field work: Data collection was started and completed within 10 months from May 2015 until end of October 2015 then after 3 months done follow up test for one month at February 2016.

Ethical consideration:

The researcher approval obtained from the ethical committee before starting the study. At the initial interview a synopsis about the nature, purpose and benefits of the study, was given for each subject. **Statistical Design:**

Data collection obtained, they were organized, categorized, tabulated and statistically analyzed to evaluate the difference between pre, post and 3 months after the program as regards the various parameters. Data were presented in tables and figures using the statistical package for social science (SPSS). Statistical significant associations were assessed using percentage (%), mean, standard deviation, chi square, t-test, p value and r test.

Results:

The present study results revealed that the main age of mothers (studies group) was 37.6 ± 0.6 years, more than one third of them (37.1%) was illiterate, More than quarter of them (77.4%) were housewife, more than half of mothers (61.3%) were living in crowded housing condition, more than three quarter of them (82.3%) had insufficient income ,more than half of mothers(51.6%) had natal causes.

Study results revealed that the mean age of children was 4.5 ± 0.5 , nearly two third of them(63.7%) were boys, more than one third of them (34.7%)ranked as the third in their families, the majority (58.1%) were spastic type, majority had mild &moderate CP(58.1%),(30.6%) respectively.

Regarding of child health assessment the present study results revealed that the majority (66%) were under weight, more than three quarter (79%) of children were abnormal investigations. Regarding systemic child health problems, this study showed more than half of children were mild condition.

The present study results revealed that, statistically highly significant difference regarding total level of mothers' knowledge pre/ post program implementation in relation to most of items ($X^2 = 162.8$); pre/3 month after the program implementation ($X^2 = 128.1$) and insignificant difference between post/after 3 month later of program implementation($X^2=6.4$).

There was noticeable improvement in the mothers' knowledg detected after the implementation of the intervention program which dropped slightly 3 month after program implementation.

There was statistically highly significant difference regarding total level of mothers' practice pre/ post program implementation in relation to most of items (T=17.1); pre/3 month after the program implementation (T=128.1); and insignificant difference between post/after 3 month later of program implementation (T=0.11).

Regarding total level of mothers' practice pre/ post and 3 month after program implementation this study showed also noticeable improvement in

the mothers' practice detected after the implementation of the intervention program.

There was statistically highly significant difference regarding total level of children dependency pre/ post program implementation in relation to daily activities ($X^2 = 156.6$); pre/3 month after the program implementation ($X^2 = 158.1$) and insignificant difference between post/after 3 month later of program implementation ($X^2 = 0.47$).

There was noticeable improvement in most items in children' dependency as reported from mothers after the implementation of the intervention program.

The present study results revealed that, statistically significant positive relation was detected between total mothers' knowledge and their total practice pre, post and follow up.

There was a statistically significant positive relation between age of children and their level of dependency pre/ post and follow up.

The study revealed statistically significant positive relations between gender of children and their level of dependency pre and post intervention program.

There was a statistically significant positive relation between associated problems of children and their level of dependency pre and post intervention program.

The study revealed that, there was a statistically significant positive relation between family income and dependency of children pre and post intervention program.

Part 1: Sociodemographic characteristics and child health problems (table 1 -2)

Table (1) Distribution of mothers according to their Sociodemographic Characteristics (n=124)

Items	No	%
Age:		
18- < 30	24	19.4
30- < 45	68	54.8
45 or more	32	25.8
Mean ± SD	37.6 ± 0.6	
Mothers' education:-		
Illiterate	46	37.1
Read and Wright	32	25.8
Basic education	27	21.8
High education	19	15.3
Mothers' Occupation:-		
Working	28	22.6
Not working	96	77.4
Crowding Index:-		
>3 Crowded	76	61.3
< 3 not crowded	48	38.7
Income / month:-		
Sufficient	22	17.7
insufficient	102	82.3

Table (2): Distribution of children according to their sociodemographic characteristics and associated problems (n=124)

Items	No	%
Age:		
3	54	43.6
4	51	41.1
5 < 6	19	15.3
$\overline{X} \pm SD$	4.5 ± 0.5	
Sex:		
Male	79	63.7
female	45	36.3
Child's rank order:		
First	27	21.8
Second	28	22.6
Third	43	34.7
Fourth and more.	26	20.9
Types of CP:		
Spastic.	72	58.1
Athetoid.	22	17.7
Ataxic.	12	9.7
Mixed.	18	14.5
Child's associated problems: *		
-Hemiplegia	29	23.4
-Diplegia	23	18.5
-Paraplegia	37	29.8
-Quadriplegia	31	25.0
-Epilepsy	84	67.7
-Difficulty of hearing	29	23.4
-Mental retardation	88	70.9
-Difficulty of swallowing	124	100.0
- Difficulty of speech	124	100.0
- Difficulty of respiration	97	78.2
-Blurred of vision	36	29.0

Figure (1): Total level of mothers' knowledge toward pre / post and follow-up intervention program.

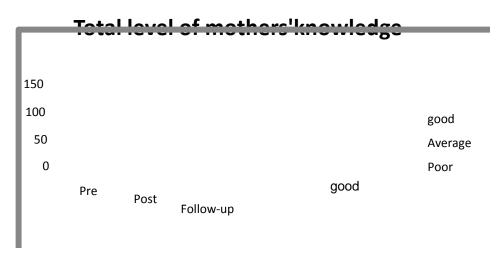


Figure (2): Total level of mothers' practices toward pre / post and follow-up intervention program.



Table (3) Correlation between mothers' knowledge and their practice (n=124)

Knowledge	practice	practice							
	Poor	Average	Good	Total No.	r .Test				
Pre:- No = 86		No =23	No = 15						
Poor	82	13	4	99					
Average	3	6	5	14	0.90**				
Good	1	4	6	11					
Post :-	No =11	No =14	No =99						
Poor	3	1	_	4					
Average	7	4	5	16	0.93**				
Good	1	9	94	104					
Follow up:-	No =9	No =17	No =98						
Poor	6	8	_	14					
Average	3	5	10	18	0.92**				
Good	_	4	88	92					

^{**} High sig. / P < 0.001

Table (4): Correlation between Associated problems of children &their mothers' total level of knowledge pre & post intervention program no =124.

Total level of knowledge		Associated problems						
	Mild No=72		Moderate No =38		Sever No =14		Total no. (124)	r- test
	No	%	No	%	No	%		
Pre	57	79.2	32	84.2	10	71.4	99	
Poor	7	9.7	4	10.5	3	21.4	14	0.80**
Average	8	11.1	2	5.3	1	7.2	11	
Good								
Post								
Poor	-	-	1	2.6	3	21.4	4	
Average	9	12.5	6	15.8	1	7.2	16	0.89**
Good	63	87.5	31	81.6	10	71.4	104	

^{**} High sig. / P < 0.001

Table (5): Correlation between Associated problems of children &their mothers' total level of Practice pre & post intervention program n=124.

	Mild		Moderate		Sever		Total	r- test
Total level of Practice	No=72		No =38		No =14		no.	
							(124)	
	No	%	No	%	No	%		
Pre	56	77.8	29	76.3	1	7.1	86	
Not done	9	12.5	5	13.2	9	64.3	23	0.77**
Done but incomplete	7	9.7	4	10.5	4	28.6	15	
Done correctly								
Post	2	2.8	7	18.4	2	14.3	11	
Not done	10	13.9	1	2.6	3	21.4	14	0.81**
Done but incomplete Done	60	83.3	30	79.0	9	64.3	99	
correctly								

^{**} High sig. / P < 0.001

Table (1) revealed that there was the mean age of mothers were 37.6 ± 0.6 .Regarding mothers' education there was 37.1% were illiterate, while 15.3% were high education. Mothers' occupation, was 77.4% were not working. Crowding index, it was noticed the 61.3% was crowded and income was 82.3% had insufficient income. Table (2): This table showed that 43.6% of children aged 3 years with mean age 4.5±0.5. 63.7% of children were males. The child's rank order was 44.4%, were first and second while these third and fourth were 34.7% and 20.9% respectively. Related to types of CP, 58.1% were spastic type while 9.7% were ataxic type. **Table (3)** This table illustrates that there was a significant positive correlation (r -Test = 0.90, 0.93, 0.93) between mothers' knowledge and their practice pre, post and follow up finding. Table (4): Show that there was a significantly positive correlation (r -Test = 0.80, 0.89) between associated problems of children &their mothers' total level of knowledge. **Table (5):** Show that there was a significantly correlation (r -Test = 0.77, 0.81) between associated problems of children &their mothers' total level of Practice pre& post intervention program. Figure (1) illustrated that the total level of mothers' knowledge after implementation program was good than befor, and follow up (83.9%, 8.9%&74.2% respectively). Figure(2) illustrated that the total level of mothers' practices after implementation program which reveal more done than before program, and follow up program implementation(99%,15%.&98%).

Discussion

Cerebral palsy (CP) is an abnormality of motor function and postural tone that is acquired at an early age, even before birth. Signs and symptoms of cerebral palsy usually show in the first year of life. The aim of this study was to evaluate the intervention program for mothers regarding dependency level of their children with CP through assessing level of mothers'

knowledge and practices related to care for their children with cerebral palsy and the dependency level of the children, Planning, Developing and implementing of educational intervention program, and evaluate the outcome of the intervention program on the level of knowledge, practice related to care and dependency level of the children.

First :-Mothers' characteristics of the studied sample

One hundred and twenty four mothers caring of children with CP were included in the present study; their main age was 37.6 ± 0.6 years. (Adam et al,2010) mentioned that the mothers should be in suitable age to be able to assume responsible appropriately toward children because young mothers are usually unprepared psychologically for parenthood. More than one third of them was illiterate .while basic education represented more than one fifth. The minority of them was high education (Klingels, et al., 2011), highlighted that when the mother is educated, this means higher income and more health awareness and ability to help throughout child life (Saunders, et al., 2014) stated that when mother' education decreases, the health risk to herself and to her children and family also increase. Also agreement with this, (Hallman, 2012). emphasized that the educated mother are able to take care of their children ,especially the CP children who need more care understanding of their needs problems. More than quarter of them were housewife also less than one quarter of them were working mothers.

Regarding crowding Index, it was found more than half of mothers were living in crowded housing condition .This factor can contributed to less of care to their children .As regard of income of studied mothers, more than three quarter of them had insufficient income ,also reported that there was significantly positive relation between mothers' income and level of dependency of their children. Badawi, and Blair, (2013) who reported positive correlation between the decreasing socioeconomic class and the severity of disability and nutritional impairment in CP children, (Adam et al,2010) who stated when unemployment

is high and/or the economy is unstable and there also may be less inclination to financially subsidize those who are disabled. There was most of parent within hassles family, people or institution to get financial help and feeling of burden with shortage of financial resources . This finding is supported by Nelson, (2013), who reported that most families find that expensive essentials are needed to care for, manage, or treat a child with CP and also found most families have ongoing, extra, out of pocket expenses that create problems for other family expenses. Although insurance, public programs and covered services are of help, they require time to access and have frustrations of their own.

Regarding perceived causes of disease during pregnancy and labor,more than half of mothers had natal causes this is confirmed with Novak,(2011) who pointed out that the dyskinetic syndromes are most likely to occur with perinatal risk factors such as asphyxia was also supported by Bersani, (2012) that the form of CP most often associated with birth asphyxia. Novak,(2011) stated that the most serious risk factors are marked immaturity and sever birth asphyxia.

regards characteristics children with CP, it was found that their mean age was 4.5 ± 0.5 where more than third aged 3 years; there was a relation between children' age and their dependency level where more than two third of children become dependent post program who aged from 4 to less than 5 years, also nearly two third of them were boys, this is in accordance with Kolawole (2014) who mentioned that CP occurs more frequently in males however, females, this contradicting with Butler ,(2014) who stated that CP occur in both sex equally.

Regarding child's rank order, it was found more than one third of studied children in this study were ranked as the third in their families, this could be due to the lack of mother tendency toward prenatal, perinatal and postnatal follow up especially in low socioeconomic status. As regards types of CP the majority (58.1%) were spastic type this agreement with Lindeman, et al 2010) who reported that children with spastic diplegia have the higher incidence. Slaman, (2010) who mentioned that most (77.4%) of the children identified with CP had spastic CP. Regarding child' associated problems (severity of disease), it was found that the majority had mild &moderate CP(58.1%), (30.6%) respectively, there was a relation between children' associated problems and their dependency level pre and post program.

Second part :- assessment and evaluation of mothers' level of knowledge

The following part of discussion focuses on the assessment and evaluation of total mothers' level of knowledge regarding to care for their children with cerebral palsy (pre ,post and 3 month after the program implementation).the present study results Showed that, after program implementation, mothers had higher good score level than pre and follow up after program implementation, which highlights on the positive effect of intervention program on mothers' knowledge. This finding is in agreement with Ahmed,, and Youssef, (2013), who emphasized that the highest percentage of mothers' knowledge were un-satisfactory before implementation of the guidelines improved immediately which implementation of the guidelines, this level of knowledge was decreased but still better than before i.e. follow up.

Third part: assessment and evaluation of mothers' level of practice:

Comparison of total score level of mothers' practice pre, post and follow up after program the present study results showed that. after program implementation, mothers were done correctly than pre and follow-up after program implementation highlighted the positive effect of intervention program on mothers' practice. Ones (2011), who stated that it is difficult for the intellectual capacity of illiterate mothers to retain practical knowledge in their memory for long time without reinforcement...

The Fourth part, discussion focuses on the statistical relations.

A-Correlation between mothers' knowledge and their practice:

Regarding to relation between mothers' knowledge and their practice, this study result showed that statistical significant positive relations were detected between them related to all items.

B-Correlation between associated problems of children and score total level of mothers' knowledge:

The present study showed that statistical significant relations between associated problems of children and level of mothers' knowledge

C-Correlation between associated problems of children and total score level of mothers' practices:

Considering the relation between associated problems of children and level of mothers' practices The present study showed that statistical significant

relations between associated problems of and total score level of mothers' practices

In summary our study finding revealed that program was affected in improving daily activities of children with CP namely their feeding, drinking, dressing, transferring, elimination skill and grooming (personal hygiene). Mothers and their children are in need for continuous training about activity of daily living of their children.

Therefore, increasing mothers' knowledge would certainly lead to improvement in their practice, their awareness about needs of children with CP and in child' independence in ADLs. This analysis confirm that intervention program had appositive impact on mothers' knowledge which was positively reflected on their practice and their awareness about their children' needs. The outcome was a better self care competencies among their children who become more independent in their daily living activities.

On summary the results of this study support the hypothesis that intervention program will improve some factors might affect on level of mother's knowledge and practices also, dependency level of their children.

Conclusion:

Improvement in the level of mother's knowledge and practices also, dependency level of their children as compared to pre implementation of the intervention program.

Recommendation:

1-Intervention sessions should be provided for mothers of cerebral palsy children about care of their children, as well as, community resources from whom they may seek assistance and support to fulfill with all activities of daily living (dependency level) of their CP child.

2-Improving mothers 'knowledge toward the importance of pre, perinatal, and post natal follow up

3-Increase the public a awareness toward care of child and available specialty center that provide care for these children through mass media such as television, pamphlets, and posters.

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