

**Effect of rehabilitation program on the
knowledge of caregivers of children with
cerebral palsy**

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Summary:

Cerebral palsy has one of a major health problem throughout the child life and has one of the chronic diseases that required specific care and attention from community care provider (Bell, (2008).

Objective:

Investigate the effect of community based rehabilitation Through Assessment of knowledge of caregivers who are caring for their children with cerebral palsy.

Subjects And Methods

Setting:

This study was conducted at Neurology outpatient clinic of children's in pediatric hospital Ain Shams University, center Ain Shams University and center integrative society care for rehabilitation for cerebral palsy children in Zyton area.

Subjects:

The subjects of this study consisted of 150 children having cerebral palsy and attending the previously mentioned settings for rehabilitation within a period of six months, along with their accompanying caregivers. Children were selected according the following inclusion criteria: Age range between 1- 13 years. With moderate grade of cerebral palsy.

Methods:

A specially designed questionnaire sheet was used to collect data by phases.

Socio- demographic characteristics of the child as age, sex., Details about cerebral palsy as age at onset, duration, cause, This part consisted of questions to assess caregiver's knowledge about cerebral palsy such as definition, disability, self- care, fits and general healthcare. preparatory phase, pilot study and actual implementation.

Results:

The highest percentages were first order in the

birth (48.7%), and had two siblings (54.0%). Slightly more than one- fifth of them were following special education (25.3%), and had primary education (26.0%). More than one of the caregivers was mothers (57.3%), followed by fathers (24.7%). About two- thirds of caregivers were housewives (63.3%), with more than half illiterate or could read and write, (21.3%) and (34.0%). After implementation of the program statistically significant improvement were noticed in caregivers' knowledge in all tested areas ($p < 0.001$). These improvements continued to increase throughout the follow- up phase, except for the health care, which showed a very slight decline.

Conclusion:

The most common causes of cerebral palsy were labor related (asphyxia, hemorrhage, and head injury). Mothers are considered the primary caregiver among majority of CP child.

Introduction:

Cerebral palsy has one of a major health problem throughout the child life and has one of the chronic diseases that required specific care and attention from community care provider. The birth of child who has cerebral palsy is a potentially traumatic event for parents in the past each family was often told to put their child in an institution and forget about him (Bullough (2004).

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The incidence of cerebral palsy is from 100 to 600 cases/ 100,000 all over the world, there are almost 300.000 affected children in the United States (Neff and Weiss, 2004).

Cerebral palsy is defined as difficulty in controlling the voluntary muscles due to damage to some portion of the brain furthermore the damage is fixed, and does not become progressively greater

(UNESCO 2006).

Magnitude of the problem in Egypt: several studies have been conducted trying to reach an estimate of the magnitude of the problem of disability. Because of lack of agreement and standardization of definitions and procedures variable estimates were reached. The estimated prevalence varies between 11.8% and 5.6%. It is generally accepted that 5-10% of the populations have significant disabilities that need rehabilitation interventions. (WHO, (2006)

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Methods:

A specially designed questionnaire sheet was used to collect data.

Tool of data collection:

An interview sheet was designed by the researcher for data collection, based on review of pertinent literature. It was validated through experts' opinions. It consisted of the following phases:

- ✧ Preparatory phase: This phase involved review of current and past available literature and theoretical knowledge, using books articles.
- 1. Assessment Phase: The actual field work

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started from first week of March (2008) to second week of October (2008), the researcher was available in the study settings two days per week (Sunday and Wednesday) in the morning. The researcher started by introducing herself to each parent accompanied the child; the researcher found the largest number from caregivers and giving them brief idea about the study and its purpose, caregiver's responses to items of the interviewing questionnaire was filled by the researcher each caregiver was interviewed for 20-30 minutes depending upon their readiness and level of education.

2. Program construction: this program for caregivers and children was designed by the researcher according to the caregivers needs regarding cerebral palsy. It was constructed, revised and modified from the related literature to upgrade the caregiver's knowledge and practices regarding care of their children with cerebral palsy, the contents were prepared according to caregiver's level of understanding in simple Arabic language.
3. Program implementation: The program was carried out at the study settings. The total number of sessions was (12) to cover the content of the program mothers were divided according to their level of education into 2 main groups educated and illiterate, then each group was subdivided into 5 groups, 10 mothers in each group according to their children's condition and types of cerebral palsy. The duration of each session was 45 to 60 minutes including periods of discussion of Sessions, started at 11 Am which was a suitable time

form for mothers because the time from 8:30 to 11:0 Am, they were so busy with doctors, physiotherapist and making investigations for their children. The researcher started each session with a summary for the previous one. Methods of teaching were lectures, group discussion, demonstration and redemonstration. Proper audio-visual material was used such as handout, color posters, transparencies, video tapes, cassettes

- ✕ Evaluation: After the completion of the program contents, the post test similar to pre test was done to the caregivers for measuring knowledge, needs, problem and practice regarding care of their children.
- ✕ Administrative Design: An official permission was taken from the director of Neurology outpatient clinic of children's Hospital, center Ain Shams University and complete center for rehabilitation in Zytou area.

Results:

Slightly more than two fifth (40.7%) of sample was six years in age. They had equal sex distribution. The highest percentages were first order in the birth (48.7%), and had two siblings (54.0%). The onset age was less than two years for the majority (86.7%), The most commonly reported causes of cerebral palsy were those related to child labor (40.7%), and pregnancy (32.7%). The majority reported epilepsy as the onset symptom (76.7%), while mental retardation was the least mentioned (6.7). About one-third of the cases had mixed type of cerebral palsy (31.3%). less than half of the children had other congenital anomalies (51.3%), and the majority had fits (73.3%). It is evident that at the pre-test the percentages of caregivers with satisfactory knowledge were low, with the lowest being related to cerebral palsy itself (23.3%). On the other hand,

slightly more than half of the caregivers had satisfactory knowledge about disability (51.3%) After implementation of the program statistically significant improvement was noticed in caregivers' knowledge in all tested areas ($p < 0.001$). These improvements continued to increase throughout the follow-up phase, except for the health care domain, which showed a very slight decline. The relation between caregivers' pre-program knowledge about cerebral palsy and child's disease characteristics was presented in the study. It points to statistically significant relations with special education ($p = 0.045$), type of cerebral palsy ($p = 0.049$), type of paralysis ($p = 0.02$), posture ($p = 0.01$), and sensory loss ($p = 0.03$). It is evident that the percentages of caregivers with satisfactory knowledge were higher with following special education, flaccid type of cerebral palsy, paralysis of one limb, absence of abnormal posture, and presence of sensory loss. No relations of statistical significance were found between caregivers pre-program. Knowledge about cerebral palsy any of the follow-up characteristics.

Table (1): Socio-demographic characteristics of cerebral palsy children in the study sample (n=150)

Items	No =150	%
Child Age (Years)	1-<3	39 26.6
	3-<6	50 33.3
	6+	61 40.7
Gender	Male	75 50.0
	Female	75 50.0
Order:	First	73 48.7
	Middle	45 30.0
	Last	32 21.3
Number Of Siblings	1	38 25.3
	2	81 54.0
	3+	31 20.7
Education	Below Age	80 53.3
	Primary	39 26.6
	None	25 16.7
Follow Special Education	Yes	38 112
	No	25.3 74.7

Describes the Socio demographic characteristics of cerebral palsy children. Slightly more than two fifth (40.7%) of them were six years age or order, and they had equal sex distribution. The highest percentages were first order in the birth (48.7%), and had two siblings (54.0%). Slightly more than one-fifth of them were following special education (25.3%), and had primary education (26.0%).

Table (2): Socio demographic characteristics of caregivers of children with cerebral palsy in the study sample (n=150)

Items	No =150	%
Caregivers Age	<30	30- 40+
	48	56 46
	32.0	37.3 30.7
Relation To Child	Mother	86 57.3
	Father	37 24.7
	Grant Parents	17 11.3
	Siblings/ Uncles	10 6.7
Job	Working	55 36.7
	Housewife	95 63.3
Family Income (LE/Month)	<200	15 10.0
	200-	82 54.7
	300+	53 35.3
Education	Illiterate	32 21.3
	Read/ Wiite	51 34.0
	Basic/ Secondary	42 28.0
	University	25 16.7

Regarding caregiver's socio-demographic characteristics, shows an almost equal distribution of the sample in the three age categories between less than 30 and 40 or order. More than one of the caregivers was en's mothers (57.3%), followed by fathers (24.7%). About two-thirds of caregivers were housewives (63.3%), with more than half illiterate or could read and write, 21.3% and 34.0% respectively. The family income was between 200 and 300 pounds per month for more than half of the families (54.7%).

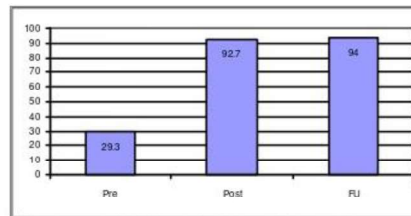
Table (3): Disease characteristics of cerebral palsy children in the study sample (n=150)

	Items	Frequency	Percent
Onset Age(Years)	<2	130	86.7
	2-<6	12	8.0
	6+	8	5.3
Duration Of Illness (Months)	<6	66	44.0
	6-<12	49	32.7
	12-<24	29	19.3
	24+	6	4.0
Cause of cerebral palsy in child	Hereditary	4	2.7
	Pregnancy related (bleeding, eclampsia, etc)	40	32.7
	Labor related (asphyxia, hemorrhage, head injury).	61	40.7
	Post labor (infection, hypoglycemia, hypothermia)	22	14.7
	Other (Jaundice, encephalitis, congenital anomaly)	14	9.3
Symptoms At Onset	Delayed Movement	35	23.3
	Spasticity	21	14.0
	Flaccidity	27	18.0
	Mental Retardation	10	6.4
	Loss of one of the senses	39	26.0
	Epilepsy	115	76.7
	Other	9	6.0
Type of cerebral palsy (CP)	Flaccid	33	22.0
	Fits	22	14.7
	Tremor	25	16.7
	Mental Retardation	16	10.7
	Compound	7	4.7
	Mixed	47	31.3
Other Congenital Anomalies	Yes	73	48.7
	No	77	5.3
Child Has Fits	Yes	110	73.3
	No	40	26.7
	On Treatment For Fits	110	100.0

The characteristics of child illness are presented in table 3, which demonstrates that the onset age was less than two years for the majority (86.7%), and its duration mostly less than one year. The most commonly reported causes of cerebral palsy were those related to child labor (40.7%), and pregnancy (32.7%) The majority reported epilepsy as the onset symptom (76.7%), while mental retardation was the least mentioned (6.4%) About one-third of the cases had mixed type of cerebral palsy (31.3%) Slightly less than half of the children had other congenital

anomalies (51.3%), and the majority had fits (73.3%) that were treated among all of them (100.0%).

Fig. (1): Caregiver's total knowledge related to cerebral palsy and disability throughout program phases



Pre-Post ($\chi^2=126.45, p=0.001$) Pre-FU ($\chi^2=132.68, p<$

Displays caregivers' total knowledge about cerebral palsy throughout program phases. It indicates that only less than one- third of them had satisfactory knowledge at the pre-test (29.3%). This percentage rose to (92.7%) at the post- test, and (94.0%) at the follow-up.

Table (5): Relation between caregivers' pre-program knowledge about cerebral palsy and disease characteristics.

Items		Satisfactory Knowledge		Unsatisfactory Knowledge			
		No.	%	No.	%		
Duration Of Illness (Months)	<6	17	25.8	49	74.2	1.92	0.38
	6-<12	18	36.7	31	63.3		
	2+	9	25.7	26	74.3		
Follow Special Education	Yes	16	42.1	22	57.9	4.00	0.045
	No	28	25.0	84	75.0		
Onset Age(Years)	<2	39	30.0	91	70.0	0.21	0.65
	2+	5	25.0	15	75.0		
Number Of Symptoms	1	11	22.9	37	77.1	1.40	0.27
	2+	33	32.4	69	67.6		
Type of cerebral palsy (CP)	Flaccid	17	51.5	16	48.5	11.13	0.049*
	Fits	4	18.2	18	81.8		
	Tremor	7	28.0	18	72.0		
	Mental Retardation	3	18.8	13	81.3		
	Compound	1	14.3	6	85.7		
	Mixed	12	25.5	35	74.5		
Child Has Fits	Yes	32	29.1	78	70.9	0.01	0.91
	No	12	30.0	28	70.0		
Locomotor System (Paralysis)	One Limb	28	41.8	39	58.2	11.46	0.02*
	Hemiplegia	8	22.2	28	77.8		
	Paraplegia	5	25.0	15	75.0		
	Triplegia	1	5.3	18	94.7		
	Quadriplegia	2	25.0	6	75.0		
Abnormal Posture Muscle	No	19	44.2	24	55.8	6.42	0.01*
	Yes	25	23.4	82	76.6		
Mentally Retarded	Relaxed	24	31.2	53	68.8	0.26	0.61
	Flaccid	20	27.4	53	72.6		
Child Has Fits	No	7	18.9	30	81.1	2.57	0.01*
Locomotor System(Paralysis)	Yes	37	32.7	76	67.3		
Abnormal Posture	No	3	11.5	23	88.5	4.80	0.03*
	Yes	41	33.1	83	66.9		

*Sig or p=<0.

The relation between caregivers' pre-program knowledge about cerebral palsy and child's disease characteristics are present in this study. It points to statistically significant relations with following special education (p=0.045), type of cerebral palsy (p=0.049), type of paralysis (p=0.02), posture (p=0.01), and sensory loss (p=0.03). It is evident that the percentages of caregivers with satisfactory knowledge were higher with following special education, flaccid type of cerebral palsy, paralysis of one limb, absence of abnormal posture, and presence of sensory loss.

Discussion:

Cerebral palsy is not a single disease. The cerebral palsies of childhood are a heterogeneous group of neurological disorders characterized by early onset and abnormal control of movement and posture (Denhoff, 2002).

Client education is a central component of the specialty practice of rehabilitation caregivers and child, the focus of education in rehabilitation is helping the individuals learn to live with disability in their own environment. The education process fosters self-care by helping the child and caregivers to acquire new information, develop new skills competently apply knowledge and skills to functional activities, develop adaptive behaviors to manage the illness or impairment and prevent further disability (Cubitt, 2006).

According to Orem's self-care model, the level of well-being is directly proportional to the level of self-care activities that the individual engages in. Therefore the goal of nursing management within this frame-work is to maximize a person's potentials for self-care.

Mother of children with disabilities reported a wide range of problems in parenting their child. Almost half of the mother's concerns centered on their child and how he or she was functioning, other sources of parental stress were medical and legal concerns as well as personal and family problems (Bjorson et al., 2003).

The two main concerns of this study are to assess caregiver tasks, needs and problems and rehabilitation for child based on the identified needs.

Socio-demographic characteristics of the study group. It is described that slightly more than two-fifths of them were six years of age or older, they had equal sex distribution, the highest percentages were first order in birth and had two siblings. Slightly more than one-fifth of them were following special education

and had primary education (Draz, 2003) stated that mothers are considered the most primary health care workers around the world. Regarding caregivers' socio-demographic characteristics, shows an almost equal distribution of the sample in the three age categories between less than 30 and 40 or older. More than one of the caregivers were children's mother (57.3%), followed by father (24.7%). About two-thirds of caregivers were housewives (63.3%), with more than half illiterate or could read and write, (21.3%) and (34.0%), respectively. The family income was between 200 and 300 pounds per month for more than half of the families (54.7%). As regards characteristics of child illness are presented in which demonstrates that the onset age was less than two years for the majority, its duration mostly less than one year. The most commonly reported causes of cerebral palsy were those related to child labor (40.7%), and pregnancy (32.7%). The majority reported epilepsy as the onset symptom (76.7%), while mental retardation was the least mentioned (6.7%). About one-third of the cases had mixed type of cerebral palsy (31.3%). Slightly less than half of the children had other congenital anomalies (51.3%) that were treated among all of them (100%).

On assessing caregiver's knowledge related to cerebral palsy, disability, self-care, Epileptic fits and health care before program had unsatisfactory score level can not clarify them but the post and follow up program implementation the majority of them can identify and satisfactory found high significant between pre, post and follow up program. As regarding follow up site and frequency among cerebral palsy children in the study sample demonstrates that about two-thirds of the children had no nearby center for follow up, and they followed at hospitals (56.7%). The frequency of follow-up in outpatient clinic was only once for more than two-fifths of the children (43.3%), and in about

one third of the cases, caregivers got no responses to their queries (30.7%).

Caregivers' knowledge related to cerebral palsy and disability throughout program phases showed the effect of the intervention program on caregivers' knowledge is demonstrated in this study. It is evident that at the pre-test the percentages of caregivers with satisfactory knowledge were low, with the lowest being related to cerebral palsy itself (23.3%). On the other hand, slightly more than half of the caregivers' had satisfactory about disability. After implementation of the program, statistically significant improvement were noticed in caregivers' knowledge in all tested areas ($p < 0.001$). These improvements continued to increase throughout the follow-up phase, except for the healthcare area, throughout the follow-up phase, except for the health area, which showed a very slight decline. As regards displays caregivers total knowledge about cerebral palsy throughout program phases. It indicates that only less than one-third of them had satisfactory knowledge at the pre-post (29.3%). this percentage rose to (92.7%) at the post-test and (94.0%) at the follow-up. Regarding to relation between caregivers' pre-program knowledge about cerebral palsy and child's disease characteristics are present in this study. It points to statistically significant relations with following special education ($p=0.045$), type of cerebral palsy ($p=0.049$), type of paralysis ($p=0.02$), posture ($p=0.01$), and sensory loss ($p=0.03$). It is evident that the percentages of caregivers with satisfactory knowledge were higher with following special education, flaccid type of cerebral palsy, paralysis of one limb, absence of abnormal posture, and presence of sensory loss. Regarding to illustrate the relation between caregivers' pre-program knowledge about cerebral palsy and the follow-up characteristics. It points to no relations of statistical significance with any of the follow up characteristics.

Conclusion:

Based on the finding of the present study, it can be concluded that:

1. The present study finding revealed that statistical significant relation between overall caregiver's knowledge related to cerebral palsy, disability, self-care, and health care pre- post and pre- follow up program phases was satisfactory.
2. The present study finding revealed that statistical significant in correlation matrix of scores of caregiver's knowledge, practice, dependence in daily activities and needs of cerebral palsy children.
3. The present study finding revealed that statistical significant in scores of caregiver's knowledge program attendance.

Recommendations:

Based on the current study finding the following recommendations are to be presented:

1. The need for continuous education and parental training program for caregivers and their families about CP children to acquire them with Knowledge, practices & physiotherapy.
2. Develop rehabilitation program by all hospital, units, for caregiver's and child, through a simple booklet (related to disease, treatment, diet, practice related to rehabilitation) with updated knowledge and instructions about cerebral palsy.
3. Encouraging continuous educational programs for caregiver's dealing with child cerebral palsy in center to enhance their knowledge and skills about rehabilitation (before, during and after session)
4. Provision the guideline booklet to caregiver's to help them in improving their knowledge and practice by needed information and apply this guideline booklet and given to all newly

- admitted child in all center (hospital) units.
5. Developing Future researches to investigate physical, psychological, social, spiritual needs that affect on compliance of the CP children.
 6. Improving the public awareness toward care of child and available specially center that provide care for these children through mass media such as television, pamphlets and posters.
 7. Emphasize the importance of raising the awareness of the parents regarding the referral places for caring the children with CP.
 8. Sharing of the family members with the team health care to get the optimal result.
 9. Stress on importance of home care services and follow-up for critical condition or sever CP children to decrease burden on caregiver's.

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	المختص
تلك الاماكن.	تأثير البرنامج التأهيلي على معلومات مقدمي الخدمة لأطفالهم
٦. وجد أن غالبية الاطفال يعانون من شلل مختلط ٣١,٣%.	المصابين بالشلل الدماغي
٧. أوضحت الدراسة ان حوالي ٧٦,٧% يعانون من صرع وفقدان في احدى الحواس حوالي ٢٦%.	واحد من أهم المشاكل الصحية التي تؤثر على حياة الاطفال المصابين به كما يعتبر صدمة للقائمين على الرعاية
٨. كان هناك اختلاف ذو دلالة احصائية عالية تجاه رعاية الوالدين لأطفالهم المصابين بالصرع أثناء وبعد النوبة قبل عن بعد البرنامج.	به من الاهل ولاقارب ولان الطفل المصاب يحتاج الى رعاية مستمرة من مقدمي الخدمة والرعاية الصحية بالمجتمع بالإضافة الى الجهد والمال المبذول من الاهل لرعاية هؤلاء الاطفال.
٩. وجد أن هناك اختلاف ذو دلالة احصائية عالية تجاه تعامل الوالدين مع مشاكل واحتياجات الطفل قبل عن بعد البرنامج.	حجم المشكلة في مصر:
١٠. لوحظ اختلاف ذو دلالة احصائية عالية تجاه رعاية الامهات عن كيفية التعامل مع مشاكل، تدريبات اعتماد الطفل على نفسه والاعاقة الحركية والتأهيل واهميتها قبل عن بعد البرنامج.	دراسات عديدة حاولت في الوصول لتقدير حجم المشكلة ولكن بعض الموافقات لم يتم الحصول عليها. يوجد اختلاف في تقدير النسبة تتراوح بين ١١,٨ الى ٥,٦ في المائة. حوالي نسبة ٥-٦ في المائة يلجأ الى التدخل التأهيلي. وفي هذا المجال نفذت وزارة الصحة برنامج تأهلي مجتمعي لخدمة هؤلاء الاطفال بهدف التعاون مع جميع أفراد الفريق الصحي لتحسين صحة هؤلاء الاطفال وتعليم الاهل كيفية العناية بهم.
١١. اوضحت الدراسة انه يوجد دلالة احصائية عالية بين معلومات الراعين على الخدمة قبل وبعد البرنامج.	ويتلخص دور الممرضة القائمة على الرعاية لهم في تعليم الاهل كافة الانشطة اليومية للتعامل الصحيح مع هذا المرض.
١٢. أوضحت الدراسة أن غالبية مقدمي الخدمة لديهم اكتفاء للمهام الخاصة بمشاكل اطفالهم الصحية.	نتائج البحث:
١٣. وجد علاقة سلبية بين سن الام واختلاف ذو دلالة احصائية بين مستوى تعليم ووظيفية الام وبين درجة تحسن ورعاية الام لأطفالها المريض.	يمكن تلخيص أهم نتائج هذا البحث على النحو التالي:
١٤. توجد علاقة ايجابية بين درجة تحسن رعاية الام لأطفالها المريض قبل البرنامج وبين التحسن بعد البرنامج.	١. أوضحت الدراسة أن ٥٧,٣% كانوا امهات و ٢٤,٧% كانوا اباء.
١٥. توجد علاقة احصائية بين الاهتمام بتأهيل قبل لبرنامج وبعد.	٢. بالاشارة الى سن الامهات وجد أن ٣٧,٣% تتراوح أعمارهم بين ٣٠-٤٠ سنة وحوالي ٣٤% يستطيعوا القراءة والكتابة و ٦٣,٣ لا يعملن.
الخلاصة:	٣. أما بالنسبة للدخل أوضحت الدراسة أن غالبية الامهات ٥٤,٧% ذات عائد دخل ضعيف لديهم عواقب لرعاية أبنائهم.
من نتائج هذه الدراسة يمكن أن نستخلص ان:	٤. بالاشارة الى سن الاطفال وجد أن ٤٠% سنهم حوالي من ٦ سنوات وعدد الاثنت مساوي لعدد الذكور.والغالبية العظمى منهم كانوا خارج المدرسة كنتيجة لمرضهم بالشلل الدماغي.
١. أطفال الشلل الدماغي يصابون بمشاكل كثيرة مصاحبة للمرض وأكثر هذه المشاكل فقد احدى الحواس والصرع والتشنجات.	٥. أوضحت الدراسة أن غالبية الامهات تتابع في مستشفيات حكومية والاقلية في مراكز خاصة ويوجد اختلاف ذو دلالة احصائية بين المتابعة في هذه الاماكن وبين درجة ارضاء الوالدين تجاه الرعاية لأطفالهم في
٢. كثير من مقدمي الخدمة ليس لديهم معلومات عن طبيعة مشاكل طفلهم المصاب بالشلل الدماغي وكيفية التعامل معه قبل البرنامج.	
٣. غالبية مقدمي الخدمة لديهم مهام (احتياجات) ناتجة عن احتياج طفلهم المصاب.	
٤. كان هناك علاقة احصائية بين معلومات مقدمي الخدمة قبل لبرنامج التدريبى وبعد البرنامج.	