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EFFECT OF SUPPORTIVE CARE FOR MOTHERS ON WEIGHT GAIN OF THEIR CHILDREN WITH CLEFT PALATE

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ABSTRACT

Cleft palate (CP) or palatoschisis is a congenital incomplete closure of the mouth roof (palate) as a result of the failure of fusion of the palate during embryonic development, failure to detect and diagnose CP early after birth can exacerbate the problem and contribute to weight loss especially in isolated CP. Nursing care must not focus on the children alone, but also involve their mothers and not just given immediately before and after the surgical procedure, but from detection of the CP along with the treatment journey. The aim of the current study was to evaluate the effect of supportive care for mothers on weight gain of their children with CP. Time series quasi -experimental research design was utilized to fit the aim of the current study. The study was conducted in the out-patient clinic at Cairo University Specialized Pediatric Hospital. A purposive sample of 60 mothers of children who diagnosed as isolated CP or associated with repaired cleft lip up to two years old have participated in the study. Data were collected using the following tools: Structured interview questionnaire, Egyptian Growth Curve Chart (EGCC) (2002), Mothers' knowledge assessment sheet, and Mothers' practice assessment checklist. The study results revealed that mothers who received supportive care had a higher mean score of knowledge and improved levels of practice regarding care of their children with CP than those in the control group. Children of mothers who received supportive care had a higher mean of body weight gain than those in the control group. The results also demonstrated that there were statistically significant positive correlations between children' weight gain and total mean score of mothers' knowledge in the immediate post-test and two weeks after surgery. The study results concluded that, the application of supportive care for mothers of children with CP has a positive effect on their children body weight gain.

KEYWORDS: *Cleft Palate, Supportive Care, Mothers of Children with Cp, Pre and Post-Operative Care of Child with Cp*

INTRODUCTION

CP result from the failure of the mesenchymal masses of the lateral Palatine processes to meet and interfuse with each other, with the nasal septum, and/or with the posterior margin of the primary palate, which may be either unilateral or bilateral [1]. Palate provides a barrier between the respiratory tract and the alimentary tract. Oral intake is proficient through two separate activities, the generation of suction force (negative intraoral pressure) and swallowing [2].

It occurs in the first 9th weeks of fetal life. Clefts can be divided into four general categories: (those involving the lip and the primary palate; (2) those involving lips and palate; (3) those in which the palate alone is affected; and (4) congenital insufficiency of the palate. The term "palate" includes hard and vellum or, soft palate [3].The approximate incidence ratio of CL/P has been reported as 1:700 live births. CL/P is the second most common congenital malformation following clubfoot. [4] Stated that, CL/P occurs in 1 in 500 to 1000 live births [5]. Several distinct genetic and environmental risk factors have been identified and confirmed in non-syndromic CL/P [6]. Problems that result from the presence of CP such as failure to gain weight, because of feeding problems, the flow of milk through nasal passages during feeding, poor growth, repeated ear infections, and speech difficulties [7]. The nurse in the cleft team initiates a close relationship between the infant and the mother, and supports the family in what is best for them. Counseling for feeding is initiated at birth in the maternity and then after neonatal cleft lip repair. The information is important for the mothers gain confidence in having a child with CLP/CP [8]. [9] Emphasized that supportive care is provided to meet the physical, informational, practical, emotional, spiritual, and psychosocial needs during pre surgical surgical, post surgical and follow up phases. The category of informational needs is directly concerned the medical team specially nursing specialty for mothers, counseling because nurses are in direct contact with them. Partnership of mothers through providing information needed to enhance them to share in their child care and empower them to take decisions regarding their child's treatment options. Professional partnership provides mothers with a feeling of control over the situation stay optimistic and develop strategies that directly could benefit their children to be healthy members in the community later on [8]. Needs of mothers to be well-informed about their child's defect and how to cope and progress with them also needs knowledge about arrangement of treatment and different specialties needed to be involved in the care of their children in a particular time. Verbal and written format information about challenges that can face them and possible results with progress which associated parallel to the growth of their child this format is important to be a reference for the mothers in case of unavailability of health professionals [7].

METHODS

Operational Definition

Supportive care in the current study, supportive care is defined as provision of the mothers of children with CP knowledge related to congenital anomaly and practice for their children, including feeding during the pre-operative and post-operative and follow-up periods.

Aim of the Study

The aim of the current study was to evaluate the effect of supportive care for mothers on weight gain of their children with CP.

Research Hypotheses

- Mothers who receive the supportive care will have higher mean scores of knowledge related care of children with CP than those who will not.
- Children of the mothers who receive the supportive care will gain weight more than those who will not.

Research Design, Participants & Setting

A time series quasi-experimental research design was utilized to fit the aim of the study. The study was conducted

in a pediatric outpatient clinic at Cairo University Specialized pediatric Hospital. A purposive sample of 60 mothers of children, who diagnosed as isolated CP or associated with repaired CL up to two years old. The first 30 children with their mothers was considered as a control group who received the hospital routine care. The second 30 children and their mothers were participated as a study group who exposed to the supportive care.

Ethical Considerations

An official permission was obtained from the research ethics committee to carry out the study. A written informed consent was obtained from the children's legal guard by the research investigator after complete description of the purpose and nature of the study in order to obtain their acceptance as well as to gain their cooperation. Children and their mothers were informed that participation in the study is voluntary; mothers have the right to withdraw from the study at any time without giving any reason and without any effect on the care of their children. Confidentiality was assured to children and their mothers. For ethical consideration, data were collected firstly from the control group than the study group.

Data Collection Tools

Data were collected using the following tools: structured interview sheet used to collect personal data about the child; his/her family, **Egyptian Growth Curve Chart (EGCC) (2002)** :- Standardized tool adopted from Cairo university. Diabetic endocrine and Metabolic Pediatric Unit and the National Research Center–Cairo, in collaboration with Wright State University. School of Medicine. Department of Community Health Lifespan, Health Research Center. From a sample size of 33189 boys and girls (birth- 21years) to assess the weight gain of the children by plotting weight of the child on the chart for both genders by the research investigator to evaluate the effect of mothers' practice regarding care on their child's weight. **Mother knowledge assessment sheet:-** it was developed by the research investigator to assess: A Mothers' knowledge regarding CP and related preoperative care such as (definition of CP, causes, types etc),B Mother's knowledge regarding post-operative care of children with CP such as (positioning immediately, feeding time and type-restraining-wound care etc.).**Mothers' practice assessment checklist**:- was developed by the research investigator to assess, Self-reported practice of mothers regarding (feeding position, feeding devices, time of feeding…etc.).

Scoring System

To mothers' knowledge regarding CP and related care; each correct response took "2" scores, the incomplete one took "1" score and the wrong response or not known took zero. The total scores were converted to 100%, and then categorized as follows: the total score less than 50% was considered as unsatisfactory, while a score of 50% and more was considered as satisfactory level. For mothers' self-reported practice regarding CP feeding; each correct response took "1" scores, and the wrong response or not known took zero. The total score was converted to 100%, and then categorized as follows: the total score less than 60% was considered as unsatisfactory, while a score of 60% and more was considered as satisfactory level. The ffect of mothers' practice was evaluated by the weight of the child, which is the best indicator for proper growth of the child.

Data Collection Procedure

The study was carried out in three phases: preparatory, implementation and evaluation phases.

Preparatory Phase

Involve preparation of the study tool and testing its validity. Before conducting the study an official permission was obtained from the director of CUSPH and permission from the heads of outpatient surgical clinic. The research investigator introduces herself to the children's mothers who fulfill the inclusion criteria. Written consent was attained after explanation of the aim of the study. The research investigator filled the structured interview on individual bases from the both groups. Before the teaching sessions, the mothers in both groups will be exposed to pre/test.

Implementation phase

The implementation phase consisted of two instructional sessions provided for mothers in the study group during the preoperative period of their children with CP. The first session was given about knowledge regarding CP and related care, such as definition, causes, types, problems associated with CP, treatment of CP, pattern and methods of feeding and preoperative care. Materials such as special treats for CP children were presented to mothers to be oriented about different options or methods for feeding which can be used for their children with CP.

The research investigator provided them with an illustrated Arabic flyer designed by the researcher that contain eating recipes for their children to achieve proper weaning for those who start it, practice aiming to increase children weight gain, and a mother's guide contains pictures and explanation about CP and related care, such as CP definition, types, feeding position, feeding devices, weight monitoring, pre and post operative care was given to them as a reference. Children with weight gain problems related to digestion and type of milk were referred to an outpatient nutritional specialist then cases were followed up several times by the researcher to ensure the improvement in their condition. After completion of mothers' teaching session, they were exposed to immediate post-test to evaluate the impact of supportive care on mother's knowledge regarding CP and related care.

The second instructional session was carried out in the third visit two weeks before surgical correction of CP, while mothers come to the hospital to check their laboratory results needed for the surgery. The session encompassed elements about postoperative care, such as proper positioning immediately after surgery, time of postoperative feeding, types of feeding which can be used and wound care. Weight of children was measured and recorded using EGCC 2002 for both genders.

Evaluation Phase

The study and control groups were exposed to two weeks before surgery, then two weeks after surgical correction to tool 3 and 4 to evaluate the mothers' knowledge regarding CP and related practice. Also the weight of their children was measured and recorded using the tool (2) for both groups two weeks pre operatively and two weeks post operatively. The data collection took about 0ne year duration, started from September 2016 to September 2017.

Tools Validity and Reliability

Data collection tools were developed after extensive reviewing of literature. The tools were reviewed by 5 experts in pediatric surgery nursing, and pediatric plastic surgery to test the content and face validity of the tools. The tools were examined for content coverage, clarity, relevance, applicability, wording, length, format, and overall

appearance. Based on the experts` comments and recommendations; minor modifications had been made such as rephrasing and rearrangements of some sentences. Reliability of tools was performed to confirm its consistency using Cronbach's alpha and the results were r = 0.75.

Statistical Design

The collected data were, coded, categorized, tabulated, and analyzed using (SPSS 21.0). Descriptive data were expressed as a mean and standard deviation. Qualitative data were expressed as frequency and percentage. Chi-square was used to detect the relation between mothers' knowledge based on their selected personal variables. Comparison of means was performed using paired-sample t-test. Correlation among variables was done using Pearson correlation coefficient. The significance level of all statistical analysis was at < 0.05 (P-value).

Results and Data Analysis

Part I: Children' Characteristics, Mothers' Personal Data as Well as Children' Diagnosis in Study and Control Group.

Table 1: Percentage Distribution of Children' Characteristics in Study and Control Group

Children' Characteristics	Study Group (n=30)		Control Group (n=30)		t	P
	N	%	N	%		
Age/months-						
6 > 12	21	70	28	93.3	.371	.712
12 > 24	9	30	2	6.7		
$\bar{X}$ ±SD	9.7 ± 2.94		9.5 ± 1.77			
Diagnosis:- X^2 p						
Complete CP	8	26.7	12	40	8.073	.527
Incomplete CP	14	46.7	9	30		
Complete CP with CL	6	20	7	23.3		
Partial CP with CL	2	6.7	2	6.7		
Rank within the family:-						
1st	2	6.7	3	10	15.293	.934
2nd	11	36.6	8	26.7		
3rd	8	26.7	7	23.3		
4th and more	9	30	12	40		

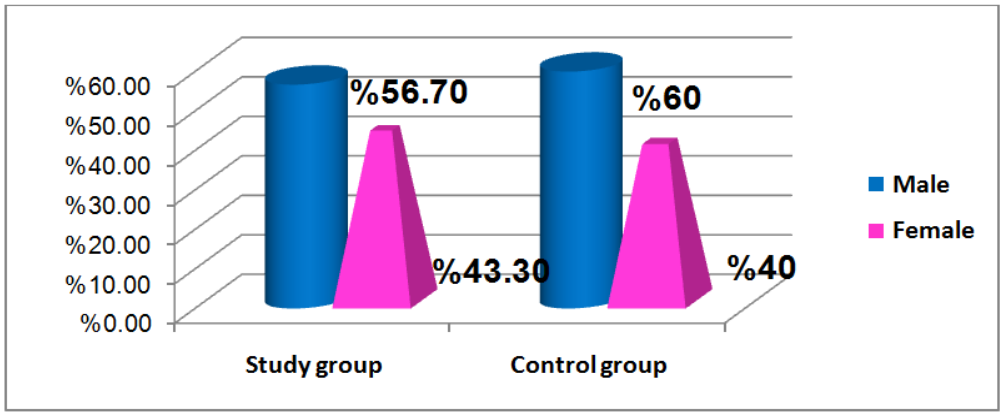

Figure 1: Children' Gender in Study and Control Group (n=60)

Table 2: Percentage Distribution of Mothers' Personal Data in Study and Control Group

Mothers' Personal Data	Study Group (n=30)		Control Group (n=30)		t	P
	N	%	N	%		
Age/years:-						
< 20	0	0	1	3.3		
20< 30	21	70	11	36.7		
30<40	7	23.3	18	60		
40 and more	2	6.7	0	0		
$\bar{X}$ ±SD	27.7± 4.66		29.7 ± 5.25		1.534	.130
Level of education:-					X^2	p
Not read and write	0	0	2	6.7		
Just read/write	5	16.7	7	23.3		
Basic education	10	33.3	5	16.7	14.90	.458
Secondary school education	15	50	13	43.3		
University education	0	0	3	10		
Place of residence:-						
Urban	14	46.7	10	33.3	.268	.605
Rural	16	53.3	20	66.7		

Part II: Children's' Weight Gain in the Study and Control Group

Table 3: Percentage Distribution of Body Weight among Children in Study and Control Group (n=60)

Child's Weight	Study Group (n=30)		Control Group (n=30)		t	P
	N	%	N	%		
Preoperative child's weight/kg :-						
Appropriate for age	18	60	16	53.3	2.039	.153
Less than normal for age	12	40	14	46.7		
$\bar{X}$ ±SD	6.29 ± 1.21		6.23 ± 0.70			

Table 4: Comparison between the Mean of Body's Weight among Children in the Study and Control Group (n=60)

Body Weight	Study Group (n=30)	Control Group (n=30)	t	P
Two weeks preoperatively:				
$\bar{X}$ ±SD	6.29 ± 1.21	6.23 ± 0.70	2.039	.153
Immediate post-test				
$\bar{X}$ ±SD	6.69 ± 0.69	6.59 ± 0.70	2.088	.041*
Two weeks after surgery:				
$\bar{X}$ ±SD	6.69 ± 0.67	6.59 ± 0.68	2.140	.037*

Part III: Mothers' knowledge about the care of children with CP

Table 5: Comparison between Total Mean Scores of Mothers' Knowledge in the Study and Control Group in the Pre-test, Immediate Post-test and Two Weeks After Surgery (n=60)

Total Mean Score Mothers' Knowledge	Study Group (n=30)	Control Group (n=30)	t	P
Pre-test:-				
$\bar{X}$ ±SD	28.17±10.47	21.17±5.07	3.29	.062
Immediate post-test:-				
$\bar{X}$ ±SD	64.80±5.91	29.33±7.24	20.79	.000**
Two weeks postoperative:-				
$\bar{X}$ ±SD	49.30±7.42	40.70±5.98	40.94	.000**

** Significant at p< 0.001

Part IV: Correlational Analysis

Table 6: Correlation between Total Mean Score of Mothers' Knowledge and Weight Gain of their Children with CP (n=60)

Children' Weight	Total Mean Score of Mothers' Knowledge	
	r	p
Two weeks before surgery	.190	.146
Immediate post-test	.396	.002*
Two weeks after surgery	.240	.065*

*significant at p <0.05

DISCUSSIONS

Based on the result of the current study infants age was ranged from 6 to less than 12 months in the majority of the study and control group in which they were prepared for palate repair this result was in the same line with [10] (cleft lip and palate association) who reported that CP repair was done between ages of 6 to 12 months off for the CP children.

As regards diagnoses among children, the results of the current study illustrated that more than one fifth of children in the study group had incomplete CP in which the females in the study are more than in the control group, whereas one fifth of them in the control group had complete CP, hence, Uppal [11] in their study about epidemiology and clinical profile of cleft patients they stated that the incidence of incomplete cleft is higher than the incidence of complete CP. This result was based on a purposive sample in which the researcher's selected cases with cleft palate to conduct the study. This result agreed with Patel [12] reported that the foremost type of clefting is a bifid uvula, occurring in 2% of the population. The second most frequent type is a left unilateral complete cleft of the palate and pre palatial structures.

Regarding children' gender, the current study illustrated that more than half of children with CP in both the study and control groups were males. This result is contradicts with [11] and [13] in their study research about the epidemiology, etiology and treatment of isolated cleft palate, they stated that theincidence of CP in females is higher than in males.

Regarding to child's order in the family the present study indicated that one third of the study group and two fifth of the control group were the 4th child or more this result was agreed with Alaswad [14] and Ize-Iyamu [15] in their research about feeding interventions in babies with cleft: a practical approach for feeding efficiency and weight gain, who found that the infant's order in the family was the 4th child or more were represented about one third of the study sample. Child's rank could influence the parents' rearing practice in some Egyptian communities.

The results of the present study revealed that more than two thirds of the mothers in the study group were between 20 to less than 30 years old with mean age 27.7$\pm$ 4.66 years old, this result is agreed with Alaswad [14] who conducted a research about feeding patterns among infants with CL and /or CP, they found that mothers age mean were 28 years old, while less than two thirds of the mothers' in control group aged from 30 to less than 40 years old with mean age 29.7$\pm$ 5.25 years old this result is in the same line with Mcheik [16] who conducted a research about infants' growth in the first two years of life after repair the mothers' age in their study was ranged from 20 to 38. Mothers' age, sometimes correlated with their perceptions as well as their knowledge.

Regarding the mothers educational level the current study revealed that half of the study group and two fifths of the control group had a secondary school (high school) this result was in accordance with Alaswad [14] who found that most of the mothers had secondary school education. Concerning place of residence Massenburg [17] in their research about Barriers to cleft lip and palate repair around the world, it was indicated that the majority of cleft patients were from rural areas this result agreed with the current study which revealed that more than half of the study group and three quarters of the control group were from rural areas.

A study by Gabriela [18] was conducted in Brazil on 381 children at a rehabilitation hospital.to assess the effect of craniofacial anomalies on weight of children under two years of age showed that there is a spontaneous recovery in approximate age of five months in early childhood even in those who are not repaired yet, the current study revealed that two thirds of the study group and more than half of the control group had normal body weight at the preoperative measurement according to Egyptian growth curve chart (EGCC).

Second time measurement of body weight three quarters of the study group had normal body weight in which it was following the preoperative instructions (supportive care) and follow up by the research investigator showing improved children's body weight on the EGCC since this improvement was on a varied period according to each case as they take a date for surgery in the list it was more than 2 months in all cases, while more than two thirds of the control group had low body weight than normal in the second time of weight measurement. This result is supported by Reilly [19] and Bahgat [20] in their study about the effect of using feeding protocol on feeding performance of children with CL/CP in Egypt, this study indicated that additional maternal support by a clinical nurse specialist can both improve weight gain outcomes and facilitate referral to the appropriate services.

Rawat [21] studied the effectiveness of structured teaching programme on the mother of CL/CP knowledge; they found that there was a statistically significant difference between the total mean knowledge scores in the study and control group on the second and third time post-test so there was an acceptance of the research hypothesis.

Clearly, the current study emphasized that there was a statistically significant difference in the immediate post-test between study and control group also in the post- test (1month after post-operative instructions) between mother's total mean knowledge scores in the study and control groups while there was no statistical difference in the pre- test between both groups.

Concerning correlation between the mothers' knowledge and their children's body weight the current study results indicated that there was no statistical significant correlation between children weight gain and total mean score of mothers' knowledge in the pre-test. Also there were significant positive correlations between children weight gain and total mean score of mothers' knowledge in the immediate post-test and two weeks after surgery. That could prove the importance of the supported care given to the mothers in which was prominent in the difference between pre-test and post- test after receiving supportive care and strengthen the researcher's hypothesis about the effect of parents' knowledge on the children's body weight. The study result can be supported by Rawat [21] who found that there was a statistical significant positive correlation between mothers' knowledge and practice in which affect directly on feeding performance which reflected on the children's body weight.

CONCLUSIONS AND RECOMMENDATIONS

The result of the current study concluded that the application of supportive care for mothers of children with CP has a positive effect on their child's body weight. Mothers who received supportive care had a higher mean scores of knowledge and improved levels of practice regarding care of their children with CP than those in the control group. Children of mothers who received supportive care had higher mean of body weight than those in the control group. The results also concluded that there were statistically significant positive correlations between children' weight gain and a total mean score of mothers' knowledge in the immediate post-test and two weeks after surgery.

Recommendations: based on the results of the current study the following recommendations are suggested raising awareness of pediatric surgical nurses about the supportive care for mothers of children with CP and its positive effect on the children body weight that can be done through periodic training sessions, integrating well trained nurses in a multidisciplinary team of craniofacial anomalies, establishing a website for mothers of children with CP contain information and images and details concerned with the congenital anomaly and related surgical procedure and prognosis with the available services for support and guidance, application of the supportive care immediately after detection of the congenital anomaly to get the best outcomes for mothers and their children.Finally; and replication of this study is warranted, this would enhance opportunities to generalize the findings to other surgical clinical settings.

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