

Effectiveness of Structured Teaching Program (STP) on Knowledge and Practice of Post-Operative Care among Parents of Children with Cleft Lip and Cleft Palate

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Abstract

It is a study to assess the effectiveness of structured teaching programme on knowledge and practice of post-operative care among parents of children with cleft lip and cleft palate in a selected hospital, Dehradun, Uttarakhand.

Objective: The main objectives of the study was to compare the post-test knowledge of parents on post-operative care of cleft lip and cleft palate in control and experimental group and to assess the post-test practice of parents on post-operative care of cleft lip and cleft palate in control and experimental group.

Methodology: Quasi-experimental, two groups pre-test and post-test designs were used in the study. The study was done in selected hospital Dehradun, Uttarakhand. The sample comprised of 60 parents of children with cleft lip and cleft palate who fulfilled inclusion criteria. All the participants who are available at the time of data collection were taken consecutively. Data was collected from participants by conducting interview schedule using structured knowledge questionnaire and observation practice checklist.

Result: The result showed that in experimental group the mean post-test knowledge score (18.90 ± 0.95) was higher than the mean post-test knowledge score (10.46 ± 1.52) in control group which was found statistically significant at $p < 0.05$. The mean post-test practice score in experimental group in day 1 was 10.40 ± 1.95 which was higher than the control group 7.00 ± 1.59 and the 't' value was 7.36. Again the mean post-test practice score in experimental group in day 2 was 11.80 ± 1.95 which was higher than the control group 6.66 ± 1.72 and the 't' value was 11.84. On third day the mean post-test practice score in experimental group was 10.76 ± 2.26 which was higher than the control group 6.43 ± 1.45 and the 't' value was 8.80. Hence the score predict that there was significant difference between the mean post-test practice in experimental and control group at $p < 0.05$ level. So there was no evidence to accept the null hypothesis, hence the researcher rejects the null hypothesis and accepted the research hypothesis.

Conclusion: It was concluded that structured teaching programme on post-operative care of cleft lip and cleft palate was effective in increasing knowledge and practice of parents.

Keywords: Effectiveness; Structured teaching programme; Knowledge and practice

Introduction

The cleft lip and cleft palate are malformation of the face that may occur individually or together [1]. The cleft lip occurs with or without cleft palate in about 1 in 1000 birth. The cleft palate occurs alone in approximately 1 in 2500 births and occurs most of 10 in females [2]. These abnormalities appear to run in families and therefore to be influenced by heredity but non genetic factors may also be involved. As per the center for disease control (CDC) data and statistics, causes of cleft and craniofacial defects and how these conditions affect children and their families by focusing on risk factors, health-care service use, access to care, quality of life, health outcomes and management and treatment of these conditions. Researcher has identified risk factors for cleft lip with or without cleft palate, including maternal diabetes,

smoking and certain medications [3]. A social stigma is created within an individual when he/she is negatively discriminated by labeling him/her different from normal. An individual's thoughts, feelings and behavior related to their physical appearance make their body image attitude [4]. Moreover, being physically attractive appears to be an advantageous trait regardless of age. Surgery, being the immediate option of dealing with certain issues related to disfigurement, is beneficial in dealing with both physical and psychological issues. Surgery usually results in increased self-esteem, self-confidence and satisfaction with appearance [5]. People think that cleft lip and cleft palate is purely a cosmetic concern, however this is not exactly true as it is also health and survival issue.

Background of the Study

Cleft lip and palate is one of the most common congenital anomalies requiring surgical treatment in children, normally commenced in the

first year of life [6]. Routine laboratory testing has minimal impact on management and outcome of orofacial cleft surgeries. However, hematocrit screening may be appropriate, particularly in clinically pale patients [7]. The Ambulatory cleft lip repair has been practiced in developed countries, but its safety has never been examined in developing countries. This study compares the outcomes of ambulatory cleft lip repair with the inpatient setting [8]. Children with cleft lips and palates have a variety of conditions and functional limitations even after the surgical correction of their problem that need to be evaluated and treated by several specialists [9]. The optimal management of the cleft lip and palate patient from birth to completion of treatment presents a formidable challenge to the plastic surgeon and the associated health care system. The multidisciplinary team approach for the management of these patients is widely accepted [10]. The early myringotomy with insertion of tube is effective to restore the function of the middle ear in cleft palate infants with SOM, so to suggest to be performed at the same time of the repair of cleft lip within the first 1-year of life [11]. Parents' desire for participation in caring for their hospitalized child, their unexpressed needs for communication and concern about the non-monetary costs of participation and also showed that parents want to participate in child care for fulfillment of their child unexpressed need [12].

More precise management of postoperative infusion is necessary for cleft patients. For patients less than six months old, the amount of intravenous infusion should be around 60% of the physiological requirements, whereas that for patients between six months and one year should be around 75% [13]. How bilateral cleft lip and palate (BCLP) cases responded differently to presurgical orthopedics (PSO) and primary lip repair (LR) based on premaxillary characteristics. The two types of BCLP outlined in this study are different from several aspects, and hence management should be modified according to each case [14]. Greater awareness of the guidelines for SBE prophylaxis is needed. Most cleft patients with a cardiovascular malformation do not require cardiac surgery and do not experience an increased rate of complications associated with cleft surgery [15]. During pre and post-operative care nurses who work continuously and closely with the patients should have knowledge, experience and ability to take excellent care of their patients and families. This can prevent complications and help their decision process, decrease parents stress and encourage better co-operation [16]. Hospitalization and surgery are stressful experiences for children and their parents. In recent years, pediatric health care has shifted toward family-centered care that is based on close and continuous involvement of the child's family members [17], hospitalized children with chronic illness, parental caregiving needs and valuing parental expertise [18].

Objectives

1. To assess pretest knowledge of parents on post-operative care of cleft lip and cleft palate in control and experimental group.
2. To determine the effectiveness of structured teaching programme on knowledge among parents of children with cleft lip and palate in experimental group.
3. To compare the posttest knowledge of parents on post-operative care of cleft lip and cleft palate in control and experimental group.
4. To assess the posttest practice of parents on post-operative care of cleft lip and cleft palate in control and experimental group.
5. To compare the posttest practice of parents on post-operative care of cleft lip and cleft palate in control and experimental group.
6. To find the association between pre-test knowledge of parents and socio-demographic variables.

Hypothesis

Hypothesis would be tested at the significant level of <0.05 .

H₁: The mean post-test knowledge score would be significantly higher than mean pre-test knowledge score in experimental group.

H₂: The mean post-test knowledge score of experimental group would be significantly higher than mean post-test knowledge score of control group.

H₃: The mean post-test practice score of experimental group would be significantly higher than mean post-test practice score of control group.

H₄: There would be significant association between pre-test knowledge score and socio- demographic variable.

Materials and Methods

Research approach indicates the basic procedure for conducting the research [19]. Quasi-experimental two group pre-test post-test design was conducted in selected hospital Dehradun. The study was confined to sixty parents (30 in experimental and 30 in control group) of cleft lip and cleft palate children who fulfilled inclusion criteria. On the first day socio-demographic characteristics of the participants were collected and pre-test was done by using structured knowledge questionnaire through interview schedule and then administered structured teaching program for one hour in the form of intervention. After fifth day of intervention, the knowledge of participants was assessed by using same structured knowledge questionnaire. The practice of participants was assessed after forty eight hours of surgery using observation practice checklist once in a day for the next consecutive three days.

Results

Section A: Analysis of socio-demographic variables of participants

The data presented in Table 1 showed that in experimental group majority 17 (56.7%) of children were in the age group of 11-20 months. The majority of sample 12 (40%) were in the age group of 26-30 years. The majority of sample 24 (80%) were mother. 15 (50%) sample had primary education. The majority of sample 18 (60%) were having Rs. 5000-10000 family income per month.

In control group majority 14 (46.7%) of children were in the age group of 11-20 months. The majority of sample 12 (40%) were in the age group of 31-35years. The majority of sample 22 (73.3%) were mother and 11 (36.7%) sample had intermediate education. The majority of sample 24 (80%) were having Rs. 5000-15000 family income per month.

S. No.	Variable	N=60			
		Experimental group		Control group	
		F	%	F	%
1	Age of the child				
	1-10 months	9	30	10	33.3
	11-20 months	17	56.7	14	46.7
	21-30 months	4	13.3	6	20
2	Age of the parents				
	20-25 yr	9	30	10	33.3
	26-30 yr	12	40	8	26.7
	31-35 yr	9	30	12	40
3	Parent's relationship with the child				
	Mother	24	80	22	73.3
	Father	6	20	8	26.7
4	Educational status of the parents				
	Primary	15	50	10	33.3
	High school	9	30	9	30
	Intermediate	6	20	11	36.7
5	Family income per month				
	Rs. 5000-10000	18	60	12	40
	Rs. 10001-15000	5	16.66	12	40
	Rs. 15001-20000	7	23.33	6	20

Table 1: Frequency and percentage distribution of age of child and parents, relationship, education and family income of participants.

The data in Table 2 showed that in experimental group 17 (56.6%) sample belongs to rural area. The majority of sample 21 (70%) had 3-4 children. The majority of sample 30 (100%) were not having history of cleft lip and cleft palate in other children of family. The majority of sample 30 (100%) were not having history of cleft lip and cleft palate knowledge.

In control group 16 (53.3%) sample belongs to rural area. The majority of sample 20 (66.7%) had 3-4 children. The majority of sample 30 (100%) were not having history of cleft lip and cleft palate in other children of family.

Section B: Analysis of effectiveness of structured teaching program on post-operative care of cleft lip and cleft palate in experimental and control group participants

Objective 1: To assess pre-test knowledge of parents on post-operative care of cleft lip and cleft palate in control and experimental group.

S. No.	Variable	N=60			
		Experimental group		Control group	
		F	%	F	%
1.	Living area				
	Rural	17	56.6	16	53.3
	Urban	13	43.3	14	46.6
2.	Number of the children in the family				
	1-2 children	9	30	10	33.3
	3-4 children	21	70	20	66.7
3.	History of cleft lip and Cleft palate in other children of family				
	Yes	0	0	0	0
	No	30	100	30	100
4	Knowledge regarding cleft lip and cleft palate				
	Yes	0	0	0	0
	No	30	100	30	100

Table 2: Frequency and percentage distribution of living area, number of children; history of cleft lip and cleft palate in other children of family; knowledge regarding cleft lip and cleft palate of participants.

S. No.	Groups	N=60			
		Maximum possible score	Knowledge score (Mean ± SD)	Range	Mean %
1	Experimental group	20	8.16 ± 2.94	06-20	40.8
2	Control group	20	7.03 ± 2.90	04-17	35.15

Table 3: Mean pretest knowledge score of control and experimental group.

The data presented in Table 3 showed that the mean knowledge score in experimental group was 8.16 ± 2.94 whereas in control group was 7.03 ± 2.90. The mean percentage knowledge of experimental group and control group were 40.8% and 35.15% respectively.

Objective 2: To determine the effectiveness of structured teaching programme on knowledge among parents of children with cleft lip and palate in experimental group.

H₀: There would be no significant difference between pre-test knowledge score and post-test knowledge score of experimental group.

H₁: The mean post-test knowledge score of would be significantly higher than mean pre-test knowledge score of experimental group at the significance level of <0.05.

The data presented in Table 4 showed that in experimental group the mean posttest knowledge score (18.90) was apparently higher than the mean pretest knowledge score (8.16) in control group. The obtained 't' value was 19.20 which was higher than the 't' table value i.e., 2.05, which indicated statistically significant at p<0.05 level. So the

researcher accepted the research hypothesis. This shows that the structured teaching programme was found to be effective in increasing the knowledge of the parents of cleft lip and cleft palate.

Objective 3: To compare the posttest knowledge of parents on post-operative care of cleft lip and cleft palate in control and experimental group.

H₀: There would be no significant difference between post-test knowledge score of parents in experimental and control group.

H₂: The mean post-test knowledge score of experimental group would be significantly higher than mean post-test knowledge score of control group at the significance level of <0.05.

S. No.	Knowledge score of experimental group	N=30		
		Mean ± SD	't' value	P value
1	Pre-test	8.16 ± 2.94	19.20	<0.001
2	Post-test	18.90 ± 0.95		

Level of sig<0.05, df=29,'t' tab value=2.05

Table 4: Pre-test and post-test knowledge score of experimental group.

The data presented in Table 5 showed that in experimental group the mean post-test knowledge score (18.90) was apparently higher than the mean post-test knowledge score (10.46) in control group. The obtained 't' value was 25.63 which was higher than the 't' table value i.e 2.000 which was statistically significant at p<0.05 level. So the researcher accepted the research hypothesis. This shows that the structured teaching programme was found to be effective in increasing the knowledge of the parents of children with cleft lip and cleft palate.

Objective 4: To assess the post-test practice of parents on post-operative care of cleft lip and cleft palate in control and experimental group.

S. No	Group	Mean ± SD	't' value	P value
1	Experimental group	18.90 ± 0.95	25.63	<0.0001
2	Control group	10.46 ± 1.52		

Level of sig <0.05, df=58,'t' tab value=2.000

Table 5: Post-test knowledge score of control and experimental group.

The data presented in Figure 1 showed that in experimental group the mean post-test practice score in day 1 (10.40), day 2 (11.80), day 3 (10.76) was higher than mean post-test practice score control group in day 1 (7.00), day 2 (6.66), day 3 (6.43) in experimental group.

Objective 5: To compare the post-test practice of parents on postoperative care of cleft lip and cleft palate in experimental and control group.

H₀: There would be no significant difference between post-test practice score of experimental and control group.

H₃: The mean post-test practice score of experimental group would be significantly higher than mean post-test practice score of control group.

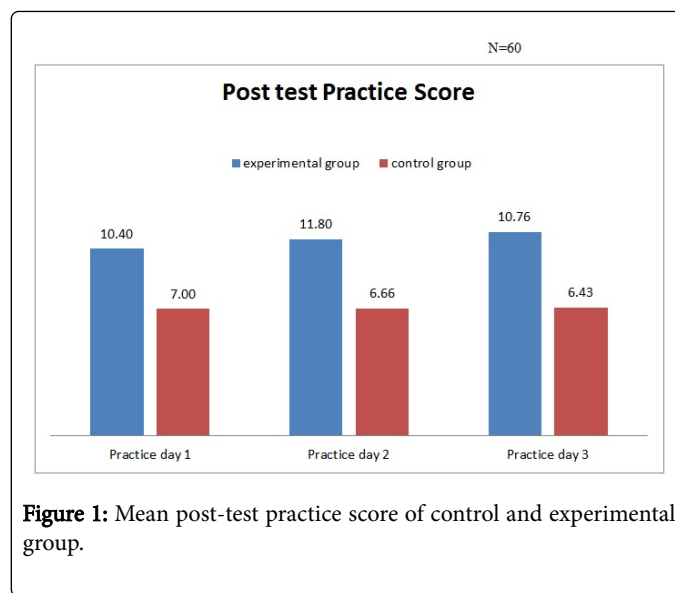


Figure 1: Mean post-test practice score of control and experimental group.

Day wise practice	N=60			
	Control group (n1=30)	Experimental group (n2=30)	't' value	P value
	Mean ± SD	Mean ± SD		
Day 1 (After 48 hrs of surgery)	7.00 ± 1.59	10.40 ± 1.95	7.36	0.0001
Day 2 (After 62 hrs of surgery)	6.66 ± 1.72	11.80 ± 1.62	11.84	0.0001
Day 3 (After 86 hrs of surgery)	6.43 ± 1.45	10.76 ± 2.26	8.80	0.0001

df=58, P<0.05, 't' tabulated value=2.00.

Table 6: Comparison between post-test practice score in experimental and control group.

The data presented in Table 6 showed that the mean post-test practice score in experimental group in day 1 was 10.40 ± 1.95 which was higher than the control group 7.00 ± 1.59 and the 't' value was 7.36. Again the mean post-test practice score in experimental group in day 2 was 11.80 ± 1.95 which was higher than the control group 6.66 ± 1.72 and the 't' value was 11.84. On third day the mean post-test practice score in experimental group was 10.76 ± 2.26 which was higher than the control group 6.43 ± 1.45 and the 't' value was 8.80. Hence the score predict that there was significant difference between the mean post-test practice in experimental and control group at p <0.05 level. So there was no evidence to accept the null hypothesis, hence the researcher rejects the null hypothesis and accepted the research hypothesis.

Section C: Analysis of association between the pre-test knowledge of participants with socio-demographic variables

Objective 6: To find the association between the pre-test knowledge of parents with socio-demographic variables.

H₀: There would be no significant association between pre-test knowledge score and socio-demographic variables.

H₄: There would be significant association between pre-test knowledge score and socio-demographic variables.

The data presented in the Table 7 showed that there was no significant association between pre-test knowledge score and age of the

child, age of the parents. From above data it can be inferred that the variables stated above did not influence the knowledge of the parents. Statistically there is no evidence to accept the research hypothesis so the null hypothesis was accepted.

S. No.	Demographic variable	N=60			
		At and above median knowledge scores	Below median knowledge scores	Calculated values	P value
1	Age of the child (in months)				
	1-10	5	14	1.91	0.38
	11-20	13	18		
	21-30	5	5		
2	Age of the parents (in years)				
	20-25	10	10	2.02	0.36
	26-30	6	12		
	31-35	6	15		

Table 7: Association of pre-test knowledge score with age of the child and parents.

S. No.	Demographic variable	At and above median knowledge scores	Below median knowledge scores	Calculated values	P value
1	Relation with child				
	Father	12	12	2.3	0.12
	Mother	11	25		
2	Educational status of the caregiver				
	Primary	12	13	1.9	0.38
	High school	5	13		
	Intermediate	6	11		
3	Family income per month				
	5000-10000	12	18	1.83	0.4
	10001-15000	5	12		
	15001-20000	7	6		
4	Living area				
	Rural	12	17	0.63	0.42
	Urban	16	15		
5	Number of the children in the family				
	1-2	10	11	1.18	0.27
	3-4	13	26		

$\chi^2=5.99$, df-2, $\chi^2=3.84$, df- 1.

Table 8: Association of pre-test knowledge score with Relation with child, educational status, family income, living area, number of the children.

The data presented in the Table 8 showed that there was no significant association between pre-test knowledge score and parents relationship with the child, educational status of the parents, family income per month, living area, number of the children in the family. From above data it can be inferred that the variables stated above did not influence the knowledge of the parents. Statistically there is no evidence to accept the research hypothesis so the null hypothesis was accepted.

Discussion

The post-operative care of the cleft lip cleft palate is an essential and crucial part of care which plays an important role in the recovery of the children. In the phase of later post-operative care most of the children is cared by their parents so the education of a parents in the care is remain vital part, the researcher understood the essentiality and conducted this research to assess the knowledge first then education is provided to the parents. The main aim of the study was to evaluate the effectiveness of structured teaching programme on knowledge and practice of post-operative care among parents of children with cleft lip and cleft palate in a selected hospital, Dehradun, Uttarakhand. The present study showed in experimental group mean posttest knowledge score was higher than the mean posttest knowledge score of control group depicting that effectiveness of structured teaching programme, which was supported by the study done on knowledge and satisfaction level of care giver of patients with cleft lip-palate at the Tawanchai cleft center. The sample size was 106 caregivers. Results showed that the 68% of mother was the caregiver, 43% had only primary education and 40% worked in field. They had moderate to good level of knowledge and a very good level of satisfaction regarding the specialized care needed.

The present study showed that there was an improvement in practice of parents in experimental group which was supported by this study and findings done by Lam LW et al. who have conducted a qualitative study on parent's experiences of participation in the care of hospitalized children in the new Territories 19 parents who had a child hospitalized for more than 48 h was participated in the study. Data were collected by tape-recorded semi-structured interview. The findings highlight parents' desire for participation in caring for their hospitalized child, their unexpressed needs for communication and concern about the non-monetary costs of participation and also showed that parents want to participate in child care for fulfillment of their child unexpressed need [20]. The present study showed that there was no significant association between per test knowledge of parents with socio-demographic variables which was supported from the study done by Dr. Sanjay Dvivedi and Dr. Jyoti Dvivedi who have conducted a study on clinical and demographic profile of the cleft lip and palate in sub Himalayan India show that the illiteracy is more as well as poverty. It seems that the education plays an important role in providing care to the child from parents and health care worker. Seventy-two percent parents of cleft lip patients were illiterate, and only 8% were graduates, the majority of patients were from the low socioeconomic class. The siblings of 1.1% of the cleft patients had similar deformity.

Recommendations

- A similar study can be replicated on large group.
- A survey can be conducted to find the incidence of cleft lip and cleft palate.

- A comparative study to find the effectiveness of teaching programme and other teaching strategy like video teaching, role play, etc.
- A descriptive study can be conducted to assess the views of parents on participation of giving care of cleft lip or palate after surgery in selected a selected hospital.

Limitations

- The result of this study must be generalized with caution as there is less sample size.
- Participated observation technique was used for observation of practice.

Conclusion

The unexpected birth of a baby with a Cleft lip and palate (CL/P) is a shocking and traumatic experience, generating anxiety for parents as well as the attendant health care team. Parents frequently leave the hospital with many unanswered questions because health care professionals do not educate them adequately. Parents of children's with CL/P want basic information in the later post-operative period, especially regarding feeding and recognizing illness. The findings of the study revealed that there was significant gain in knowledge score and practice of parents after STP, so the study concluded that structured teaching programme had a great potential for accelerating the awareness regarding cleft lip and cleft palate.

Ethical Consideration

Ethical committee permission was obtained from the ethical committee of Swami Rama Himalayan University, Dehradun and administrative permission obtained from principal Himalayan College of nursing as well as Medical and Nursing superintendent of Himalayan Hospital.

References

1. Wong S (1999) Nursing care of infants and children: Cleft lip and cleft palate. (7thedn), Mosby publishers, pp: 455-456.
2. Sharma R (2003) Essentials of pediatric nursing, cleft lip and cleft palate. (1stedn), Jaypee Brother Medical Publishers, India. pp: 344-349.
3. Centers for Disease Control and Prevention (2016) Data and statistics: Birth defects.
4. Strauss RP, Broder H, Helms RW (1988) Perception of appearance and speech by adolescent patients with cleft lip and palate and their parents. *Cleft Palate J* 25: 335-342.
5. Lefebvre A, Munro I (1978) The role of psychiatry in a craniofacial team. *Plast Reconstr Surg* 61: 564-569.
6. Bannister P, Lindberg N, Jeppesen K, Elfving-Little U (2017) Scandcleft randomised trials of primary surgery for unilateral cleft lip and palate: 3. Descriptive study of postoperative nursing care following first stage cleft closure. *J Plast Surg Hand Surg* 51: 21-26.
7. Adenekan AT, Faponle AF, Oginni FO (2012) Pre-operative haematological investigations in paediatric orofacial cleft repair: Any relevance to management outcome? *Afr J Paediatr Surg* 9: 52-56.
8. Al-Thunyan AM, Aldekhayel SA, Al-Meshal O, Al-Qattan MM (2009) Ambulatory cleft lip repair. *Plast Reconstr Surg* 124: 2048-2053.
9. Vlastos IM, Koudoumnakis E, Houlakis M, Nasika M, Griva M, et al. (2009) Cleft lip and palate treatment of 530 children over a decade in a single centre. *Int J Pediatr Otorhinolaryngol* 73: 993-997.

10. Schnitt DE, Agir H, David DJ (2004) From birth to maturity: A group of patients who have completed their protocol management. Part I. Unilateral cleft lip and palate. *Plast Reconstr Surg* 113: 805-817.
11. Li W, Shang W, Yu AH, Zhang XH, Liu YX, et al. (2007) Early treatment of middle ear disease in cleft palate infants. *Hua Xi Kou Qiang Yi Xue Za Zhi* 25: 458-462.
12. Lam LW, Chang AM, Morrissey J (2006) Parents' experiences of participation in the care of hospitalized children: A qualitative study. *Int J Nurs Stud* 43: 535-545.
13. Lixian C, Caixia G, Yuhong W, Luping Y, Qian Z, et al. (2016) Study on postoperative infusion management of cleft patients. *Hua Xi Kou Qiang Yi Xue Za Zhi* 34: 387-390.
14. El-Kassaby MA, Abdelrahman NI, Abbass IT (2013) Premaxillary characteristics in complete bilateral cleft lip and palate: A predictor for treatment outcome. *Ann Maxillofac Surg* 3: 11-19.
15. Harry BL, TeBockhorst S, Deleyiannis FW (2013) The impact of congenital cardiovascular malformations on the assessment and surgical management of infants with cleft lip and/or palate. *Cleft Palate Craniofac J* 50: 323-329.
16. Augsornwan D, Pattangtanang P, Pikhunthod K (2011) Nursing care system development for patients with cleft lip-palate and craniofacial deformities in Srinagarind hospital: Pre-post operation. *J Med Assoc Thai* 94: S114-S117.
17. Kristensson-Hallstrom I (2000) Parental participation in pediatric surgical care. *AORNJ* 71: 1021-1029.
18. Balling K, McCubbin M (2001) Hospitalized children with chronic illness: Parental caregiving needs and valuing parental expertise. *J Pediatr Nurs* 16: 110-119.
19. Polit DF, Beck CD (2004) *Nursing research: Principle and methods*. (7th edn), Williams and Williams, Philadelphia, pp: 20-40.
20. Lam LW, Chang AM, Morrissey J (2006) Parents' experiences of participation in the care of hospitalized children: A qualitative study. *Int J Nurs Stud* 43: 535-545.