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Mothers' awareness regarding cleft palate and their infants' feeding pattern

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Abstract

Background: Clefts of the lip, palate, or both are the most prevalent form of or facial congenital abnormality among neonates. In improving the health of neonates born with craniofacial deformities, neonatal nurses played a crucial role in educating parents and spreading awareness about the disease. **Aim:** to assess mothers' knowledge and practices regarding cleft palate and infant feeding patterns. The study was a descriptive study conducted at the Pediatric surgical patients Unit at Minia University Hospital for Obstetrics and Pediatrics.

Sample: A convenient sample of 30 mothers of children having cleft palate was included in this study. **The Tools of Data Collection:** 1) a pre-designed questionnaire sheet to assess mothers' knowledge about the cleft palate, 2) an assessment checklist of mothers' practice regarding Feeding patterns. 3) Observation checklists to assess feeding preparation, 4) Egyptian Growth Curve Chart (EGCC). **Results:** the majority of mothers had unsatisfactory levels of knowledge related to cleft palate. The majority of them had unsatisfactory levels of practices regarding their infants feeding. There was a statistically significant difference in total knowledge and practice scores of the mothers regarding cleft palate related to age.

Conclusion: Lack of awareness and preventative measures taken by mothers regarding cleft palate. **Recommendations:** Offer periodic in-service training sessions for mothers on the issue of cleft palate knowledge and feeding practice.

Keywords: Cleft palate, feeding pattern, mothers' awareness

Introduction

Disabling diseases and early deaths in babies are almost always the results of congenital anomalies. Orofacial clefts (OFCs) are the most frequently occurring birth defect. Congenital abnormalities (CA) are function, structure, or metabolism alterations at birth, leading to developmental delays or disabilities. The variety of symptoms and their clinical significance can vary^[1].

Neonates born with cleft lip and/or palate have additional medical, social, and psychological challenges due to the condition. Neonates with CP and CLP have unique feeding challenges that must be treated immediately. Particularly in the first year of life, they have been linked to developmental delays and malnutrition. Neonates with CP or CLP have a 32%-68% higher risk of malnutrition than other infants; however, this risk varies widely by cleft type, associated disorders, country of origin, and family income. Problems with sucking and feeding are common when this hole is present. It is uncommon for newborns to be born with a cleft lip and palate. The lip and hard or soft palate may be involved in this cleft^[2].

A newborn's birth with a cleft lip and palate (CLP) can cause many negative emotions in the parents, including sadness, shock, grief, fear, guilt, and frustration. Parents must be emotionally resilient, adapt to their new reality, and restructure their lives to meet the requirements of their neonates who have been affected. Facial appearance and functions like phonation, hearing, mastication, ventilation, and deglutition are all affected by this defect^[3].

A trained cleft palate team, working in combination with the radiology team, must explain and counsel the parents about the cleft deformity's severity and the expected outcome and repair alternatives. Early identification and counselling have advantages for the mother and infant, even though there is no intrauterine treatment for CLP. The parents will have sufficient time to learn as much as they can about the defects and adjust to their current reality.

Systematic and well-planned counselling may help patients get over the initial shock of the diagnosis. Using a multidisciplinary team to treat these individuals has become standard practice^[4].

Feeding difficulties are a major source of anxiety for parents of infants with CP or CLP. Infants with CP and CLP have a range of difficulties latching and sucking, with greater difficulty shown when the palate is involved. At the hospital, postpartum ward nurses coordinate with other medical professionals to promote infant feeding, assist new mothers in starting to breastfeed, and provide comprehensive care^[5].

Infants with cleft palate with or without lip involvement may need to be fed formula or solid foods to meet their nutritional needs; however, bonding can be facilitated by using expressed breast milk or non-nutritive feedings at the breast. Due to the emotional toll of dealing with feeding difficulties, unexpected changes in anticipated feeding strategies, and the possibility of needing to express milk regularly to maintain an appropriate supply, these families often benefit from additional monitoring and lactation support^[6].

A newborn with a cleft has the same nutritional needs as any other newborn, excluding any other systemic problems. In the first few months of life, an infant's primary focus should be maintaining an adequate nutritional intake. This continues true whether they have no deformities or severe ones, such as a cleft lip/palate. Common feeding difficulties, such as nasal regurgitation, poor sucking, frequent air intake and burping, and the resulting extended feeding time, make it difficult for newborns with cleft to maintain a proper diet. This is essential to boosting their immune systems and enabling healthy weight gain before invasive procedures are performed. For neonates with cleft palates, the most crucial factor that needs adjusting is the intake method rather than absolute nutritional alterations^[7].

Bottle feeding instruction for newborns with cleft palate involves various issues, from the different types of bottles available to parents to how to assemble and use them properly. When bottle feeding an infant with a cleft palate, it is recommended that the infant be kept upright, similar to how they were carried while breastfeeding. If the infant suffers from nasal reflux, it may help to avoid the traditional cradling position, which encourages liquid to enter the nasal canal. Similarly, an elevated side-lying position that still permits sight of the feed can be useful^[8].

Infants with CL/P often require specialized feeding approaches due to their anatomic differences, ranging from positional modifications to speciality bottle systems to ensure milk extraction. This may also require alterations to the planned feeding method due to the inability to breastfeed directly, causing additional stress. Mothers who attempt breastfeeding report challenges with the baby getting milk, latching, and gaining weight^[8].

The nurse's role is to provide the mother with the knowledge and practice to care for her infant at home before surgery (particularly in nutrition) while encouraging the parents to maintain a healthy perspective and not be excessively or inattentive. Help the mother and child bond emotionally by encouraging her to begin breastfeeding as soon as feasible^[9].

The nurse should facilitate the expression of parental anxiety and sadness. This type of communication has the potential to improve preoperative attachment. While

acknowledging the parents' worries, it's crucial to highlight the good aspects of the infant's outward appearance and offer confidence about surgical treatment. The parents ought to acquire a sense that their newborn is a valuable person from the way the infant is treated^[10].

Significance of the Study

Oro-Facial Cleft accounts for approximately half of all craniofacial deformities and is present in an estimated 1 in 700 live births. Oro-Facial clefts have a documented birth prevalence of between 3.4 and 22.9 per 10,000 live births (for cleft lip/palate) and 1.3-25.3 per 10,000 live births (for cleft palate only), according to the World Health Organization (WHO)^[11].

The highest prevalence was found in Asian populations (0.82-4.04 per 1000 live births), followed by Caucasians (0.92-2.69) and Africans (0.18-1.67). Prevalence was also found to vary by region and age group within each population. Gender and cleft pattern are other factors in the prevalence of OFC. The male-to-female sex ratio in CLP was regularly found to be 1.81.^[11]

The results of a study that was conducted at the Ain Shams University Hospital in Egypt between the years 1995 and 2009 on the topic of "congenital malformations prevalence among Egyptian children (from birth up to 18 years) and associated risk factors" showed that the CL and CP prevalence was 0.3/1000 among the study sample^[12].

Aim of the Study

This study aimed to: Assess mothers' awareness regarding cleft palate and infant feeding patterns.

Research Questions

The study answered the following questions

- Assess mothers' knowledge regarding the feeding pattern of their infants.
- Assess mothers' practices regarding the feeding pattern of their infants.

Subject and Method: A descriptive research design was utilized to achieve the aim of the current study.

Setting: This study was conducted at pediatric surgery departments & pediatric surgery outpatient clinic in Minia University Hospital for Obstetrics & Pediatrics.

Sample: A convenient sample of 30 mothers of children having cleft palate was included in this study.

Tools of data collection

Data were collected through three tools as the following:

Tool I: A Structured interviewing questionnaire:

The researcher developed the tools under the close supervision of their superiors and after examining relevant literature. The Arabic-language tools consisted of the following four parts:

Part I: Personal characteristics of the infant such as gender, age, birth weight, and current weight.

Part II: Demographic data of the mothers as age, residence, and sibling number.

Part III: Medical and family history of the mothers about cleft lip and palate.

Part IV: Mother knowledge regarding CLP and related preoperative care: it will be prepared by the research investigators which included the definition of CLP, signs and symptoms, causes, and risk factors^[13]. (Hockenberry,

Rodgers, & Wilson, 2021).

The scoring system of mothers' knowledge

The level of knowledge that mothers have of CLP and its treatment; a score of "2" is given for each accurate response, a score of "1" for each incomplete response, and a score of "0" is given for any incorrect or unknowable responses. Scores were scaled up to a possible 100%, and those with totals below 60% were deemed unsatisfactory, while those with totals of 60% or higher were considered satisfactory.

Tool II: Infant feeding pattern

The research investigator developed it to assess the self-reported practices of mothers regarding feeding, and preparation of bottle feeding for infants [14].

The scoring system of mothers' reported practice

Each right response received a "1" score, while incorrect or unknown responses received a "0" value, for mothers' self-reported practice-related CLP feeding. The final percentage was translated to a scale from 1 to 100, with scores below 60% being deemed unacceptable and those over 60% being deemed satisfactory.

Validity: A team of five pediatric nursing professionals evaluated the tool's content validity, and modifications were made accordingly. After the tool was created, it was evaluated to ensure that it was internally consistent.

Reliability: Cronbach's alpha was used to check the tools' reliability for consistency. Tool one measured mothers' knowledge about feeding infants with cleft palate, and found reliability was 0.79) and tool two about mothers' practice was 0.83.

Pilot study: A pilot research consisting of 10% (n=3) of the anticipated sample size was carried out in order to evaluate the content validity and application of the study tools, as well as to estimate the amount of time required to finish the questionnaire. The final forms were then constructed, after which certain questions and things were removed, added, or rephrased. Finally, a panel of specialists assessed the tools to ensure that they were clear, thorough, and easy to use. The study incorporated the results of the pilot sample.

Ethical Consideration: The ethical research committee of the faculty of nursing at Minia University provided its formal first approval, which was obtained by the faculty. The mothers who took part in this research project provided their formed consent in the form of an interview. For the purposes of anonymity and confidentiality, each assessment sheet was coded, and the mother's name was removed from the sheets. Prior to beginning their involvement in the study, the researcher had a direct personal conversation with the mothers to explain the objective and nature of the study.

This occurred before the mothers were asked to complete the assessment sheets. These data were kept in strict confidence and were utilized exclusively for the research. The study adhered to the standard ethical guidelines for participants in clinical research, and participants' confidentiality was protected throughout the data gathering process. The coding of the data ensured confidentiality and anonymity, and the mother retained the right to decline participation in the study without being required to provide a reason for her decision. The researcher also informed the mother about their rights to withdraw from the study at any moment without giving any reason and without having the

withdrawal have any impact on the care that they provide for their infant.

Field Work

The primary approval was obtained from a nursing faculty research committee at Minia University, which was part of an ethical research committee. Before beginning the study, administrative clearance was received from the Dean of Minia University's Faculty of Nursing to the head manager of Minia University Hospital for Obstetrics and Pediatrics. This was done so that the study could be carried out. The manager explained the study's purpose in the hopes of gaining his cooperation and being granted permission to meet with the mothers. The duration of the data collection period is approximately half a year, beginning in June of 2020-2021 and ending in December of that same year.

Statistical analysis

The data entry was completed using a personal computer that was compatible. The statistical analysis was carried out by utilizing the SPSS-20 statistical software program as well as Excel for the graphical representation of the results. The data contained within each tool was first coded, then categorized, and finally analyzed. For qualitative factors, the data were presented using descriptive statistics, such as frequencies and percentages; for quantitative variables, however, means and standard deviations were utilized. The Chi-square test was utilized to make comparisons between the qualitatively analyzed variables. When the P value was less than 0.05, statistical significance was determined.

Results

Table 1: Personal Characteristics of the studied cleft palate infants (N= 30)

Items	No.	%
Age/ years		
0-6 months	19	63.3
6-12 months	11	36.7
Gender		
Male	19	63.3
Female	11	36.7
Birth weight		
1500- 2000gm	3	10.0
2500-3000gm	21	70.0
More than 3000gm	4	13.3
Don't know	2	6.7

Table 1: Shows that 63.3% of infants' ages ranged between 0-6 months. Regarding gender, 63.3% of infants were male, and 70% of infants had birth weights of 2500-3000gm.

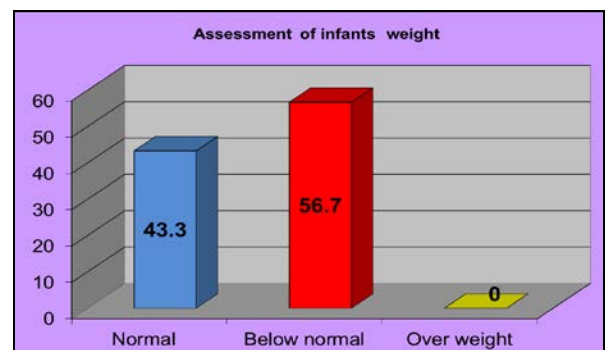


Fig 1: The studied cleft palate infant weight

Figure 1 illustrated that 56.7% of infants with cleft palate were below normal weight for age.

Table 2: Demographic Characteristics of the studied mothers' (N = 30)

Items	No.	%
Age/years		
Less than 20 yrs.	10	33.3
20-30yrs.	19	63.3
31-40yrs.	1	3.4
Residence		
Rural	25	83.3
Urban	5	16.7
Sibling number		
1-3 Children	20	66.7
4-6 Children	10	33.3

Table 2: Finds that 63.3% of mothers aged between 20-30 years old. The same table revealed that the majority of mothers (83.3%) came from rural areas. In addition, 66.7% of mothers had 1-3 children.

Table 3: Medical and family history of the studied mothers' regarding Cleft Lip or Palate (N = 30)

Items	No.	%
Have a Family history of cleft lip or palate		
Yes	3	10.0
No	27	90.0
If yes who		
Fathers	2	6.6
Uncle	1	3.4
When you discover cleft palate in your infant		
Few hours after birth	26	86.8
The first week after birth	2	6.6
The first month after birth	2	6.6
Who first discovered the cleft palate in the infant		
Doctor	28	93.4
Mother	2	6.6
Health problems or difficulties associated with cleft palate		
Feeding problems	10	33.4
Ear infection	4	13.3
Chest infection	16	53.3

Table 2 showed that 90% of mothers had no family history of cleft lip or palate. The same table revealed that the majority of mothers, 86.8% discover cleft palate in their infants after few hours after birth. Regarding health problems or difficulties associated with cleft palate, 55.3% of infants had chest infection problems.

Table 4: Total levels of the studied mothers' knowledge regarding cleft palate (N= 30)

Items	No.	%
Definition and signs and symptoms		
Satisfactory	0	0.00
Unsatisfactory	30	100
Causes and Risk factors of cleft palate		
Satisfactory	0	0.00
Unsatisfactory	30	100
Total knowledge		
Satisfactory	0	0
Unsatisfactory	30	100

Table 4 Demonstrates that 100% of mothers of infants with cleft palate don't know the definition, its causes, and risk

factors.

Table 5: Total levels of the studied mothers' practices regarding feeding of infant with cleft palate (N= 30)

Items	N	%
Feeding of the infant with cleft palate		
Satisfactory	0	0.00
Unsatisfactory	30	100
Preparation of bottle feeding for the infant with cleft palate		
Satisfactory	0	0.00
Unsatisfactory	30	100
Total practices		
Satisfactory	0	0.00
Unsatisfactory	30	100

Table 5 Revealed that 100% of mothers of infants with cleft palate had an unsatisfactory practice regarding feeding infants with cleft palate.

Table 6: Correlation between the Total Scores of the Mothers' Knowledge and Practice (N = 30)

Total Knowledge scores	Total Practice scores
r	0.044
P – Value	0.04*

Table 6 shows a positive correlation between the total score of mothers' knowledge and their practices statistically significant.

Discussion

The results of the present study revealed that more than one-third of mothers' age ranged between 20-30 years old; this result agreed with Alaswad [15] who studied infant feeding patterns and reported that the average mother of an infant with CL or CP was 28 years old, while in the control group was 30. Also, consistent with Kapos *et al.* [16] found that the majority of mothers of infants with an orofacial cleft age range from 20-34 years old and Angulo-Castro *et al.* [17] found that more than two-thirds of mothers having children with cleft palate of the study and control group age ranged from 20-35 years old.

Concerning residence, more than two third of the studied mothers of infants with cleft palate were from rural areas. This in the same line with Alaswad *et al.* [15] in their research about the effectiveness of supportive care on weight gain of the children with cleft palate, showed that the majority of cleft infants were from rural areas. On the other hand, Kapos *et al.* [16] revealed that about two-thirds of mothers of infants with orofacial clefts were from urban residences.

The current study demonstrated that most of the studied mothers had no family history of cleft lip or palate. These results agreed with Neela *et al.* [18], and Pereira *et al.*, [19] who investigated the association of cleft lip and palate in people born to consanguineous parents and found that a minority had a family history of cleft lip or palate which is consistent within his study about associated malformations of orofacial clefts who revealed that less than quarter of studied children has a positive family history of cleft lip or palate without associated malformations. On the other hand, the results of the current study disagreed with Omar *et al.* [20] in a study about the influence of consanguinity on familial clefting among Palestinians who found that more than half of children with cleft palate had a positive family

history of clefting.

Concerning the personal characteristics of infants, the current study illustrated that more than half of infants were from birth to 6 months, and more than half of infants' birth weight was 2.5 -3 kg having cleft lip with palate diagnosis. These findings agreed with the result of Nasar *et al.*,^[21] in their study about Feeding Protocol for Mothers having Infant with Cleft Lips and Cleft Palates who found that more than half of infant age was from birth to 6 months, with mean age 3.8± 3.3. Over half of the infant was 2-5 kg with a mean weight of 5.9±1.9 and had cleft lip and palate diagnosis and males. Also, Derakhshandeh *et al.*^[22] in their study regarding the prevalence of cleft lip and palate and access to rehabilitation services in the south-west of Iran stated that about one-quarter of the study group and more than two third of the control group had birth weight more than 2500 gm.

The current study revealed that more than half of infants were below normal weight for their age. These results were consistent with Madhoun *et al.*^[23] in their study about the feeding and growth of infants with cleft lip or palate who found that Infants with cleft palate had lower average weight gain (13±15) than controls group (weight 36±23).

Concerning mother knowledge mothers' Knowledge, the current study revealed that all of the studied mothers don't know the definition, causes, and risk factors of cleft palate. These results are consistent with Eltayeb *et al.*^[24], who studied mothers' knowledge and experience concerning presurgical orthopaedic management for infants with cleft lip and palate; they found that more than one-third of the mothers provided an incorrect definition of the anomaly and about one-quarter of them know the cause of the anomaly. Also, Hakim *et al.*^[25] in his study about the effect of combined education on the knowledge and care, and supportive performance of parents with children with cleft lip and palate found that there was a significant increase in knowledge of the parents in the intervention group, as compared to the control group.

Regarding mothers' practice about feeding infants with cleft palate, 100% of mothers had an unsatisfactory level of practice. These results were consistent with those of Çınar *et al.*^[10] discovered that providing nursing care to the mothers of infants born with CLP in line with the requirements of the mothers may prevent potential issues in the infants, hence supporting normal growth and development process. The term "imbalanced nutrition" was found in about four out of every five newborns (81.3%) during the first follow-up home visits that were performed for the intervention group and during the first follow-up home visits that were conducted for the mothers of the intervention group. Providing mothers with information may help reduce feelings of guilt and reduce the problems experienced while executing the responsibilities of a caregiver.

Concerning mothers' knowledge related to their age, it was found that all of the mothers had an unsatisfactory level of knowledge, and these results were inconsistent with those Abid *et al.*^[26], who studied mothers' knowledge and experience concerning presurgical orthopedic management for infants with cleft lip and palate who found that more than one-third of mothers aged 20-30 years showed a high degree of knowledge regarding CLP.

Regarding mothers' practices related to their age, it was found that all of the studied mothers had unsatisfactory practices. These results disagreed with Omar *et al.*^[20], who

studied Factors associated with the knowledge and practice of optimal breastfeeding among mothers in Dubai. He found a significant correlation between feeding practice and mothers aged 25- to 35.

The current study's results showed a positive correlation between the total score of mothers' knowledge and their practices. The study result can be supported by Ekata & Chanu^[27] in their study about the Effect of a Structured Teaching Program (STP) on Knowledge and Practice of post-operative care among parents of children with cleft lip and cleft palate found mother's feeding performance is positively correlated with their knowledge and how they feed their children.

Conclusion

The current study concluded that there was a lack of knowledge and practice of mothers having infants with cleft palate. The overall level of knowledge and practice were unsatisfactory. There was a statistically significant positive correlation between the total score of mothers' knowledge and their practices.

Recommendation

The study recommended that An educational package for pediatric surgery nurses to use with mothers to help them learn about cleft palate and proper feeding techniques. The interdisciplinary group should also plan, execute, and assess educational programs for mothers regarding feeding methods to sustain infants' growth and weight gain. Pediatric surgery nurses' knowledge of the benefits of weight gain-promoting supportive care for moms of children with CP can be increased through regular training sessions.

Conflict of Interest

Not available

Financial Support

Not available

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