

# Assessment of Mother's Knowledge and Practices Regarding Care of their Children with Cleft Lip and /or Cleft Palate

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## Abstract:

**Background:** Cleft lip and cleft palate (CL/P) are the most common congenital anomalies in newborn, the incidence of cleft lip and palate is 1 in every 500 to 1000 birth worldwide. CL/P come in many shapes and sizes, common causes include genetic causes and environmental factors. CL/P usually treated by surgical repair. **The aim of the study** was to assess mother's knowledge, and practices regarding care of their children with cleft lip and /or cleft palate. **Study design:** A descriptive research design was utilized to achieve the aim of this study. **Study setting:** this study was conducted at the In-patient and Out-patient children Surgical Department in children Hospital affiliated to Ain-Shams University Hospitals. **Study subjects,** a purposive sample composed of 70 children and their accompanying mothers regardless their characteristics were selected from the previously mentioned setting. **Tools:** **tool 1:** Structured interviewing questionnaire sheet to assess mother's characteristics and their level of knowledge and reported practices regarding CL/P and **tool 2:** Children Physical Assessment Sheet to assess the general health condition of children with cleft lip and palate. **Results,** less than half (45.7%) of the mother's had unsatisfied level of total knowledge about left lip and /or cleft palate, more than half of the mother's (55.7%) had unsatisfactory level of practice regarding feeding of their children and post-operative care. **Conclusion,** Based on the finding study, the study concluded that the research questions were confirmed by that less than half of the mother's had unsatisfied level of knowledge, and more than half of the mother's had unsatisfied level of practice. Furthermore, there were statistical significant relations between the studied mother's level of knowledge and their level of practices. **Recommendation,** establishing educational programs to improve knowledge and practices of mothers regarding care of their children with cleft and / or cleft palate.

**Key Words:** Mothers, knowledge, practices, children, cleft lip and cleft palate

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## I. Introduction

Clefts of the lip (CL) and palate (CP) are facial malformations that occur during embryonic development and are the most common congenital deformities of children. Cleft lip results from failure of the maxillary and median nasal process to fuse and cleft palate is a midline fissure of the palate that results from failure of the two palatal process to fuse<sup>[1]</sup>

Worldwide, cleft lip with or without cleft palate occurs in 1 of every 750 live birth. They are more common in boys, and isolated cleft palate occurs more frequently in girls<sup>[2]</sup>. As mentioned by<sup>[3]</sup> that CL / P is the most common congenital craniofacial abnormalities in the world, which has an incidence of 1 in 700-1000 births, with regional variances.

Cleft lip and / or cleft palate are caused by environmental factors and nutritional factors, medications, smoking and alcohol, where a high risk of developing a cleft is found in pregnancies with higher exposure to smoking. Nutritional status plays an essential role in developing cleft lip and palate, vitamin B6 deficiency is the main reasons of increased risk of clefts in addition, folic acid deficiency is the main reason of increasing clefts<sup>[4]</sup>

Surgical repair of cleft lip, usually done when infant is 3 to 6 months old, the cleft lip is wide, special procedures including lip adhesion or a molding plate device that help bring the parts of the lip closer together before the lip is fully repaired. Cleft lip repair usually leaves a small scar on the lip under the nose. At 9-12 months of age, a cleft palate usually can be repaired<sup>[5]</sup>

Pediatric nurses play an active role regarding the care of children with cleft lip and / or cleft palate. The care including pre-operative care and preparation of the infant to enter the operation room without anxiety or fear, providing post-operative care including assessment of airway patency and vital signs, observation for respiratory distress, preservation of position of the child with cleft to avoid injury to the operative site, clean the suture line, monitoring the site for signs of infection, supporting the child and parent emotional, social and psychological adjustment <sup>[6]</sup>.

The role of the mothers regarding care of infant with a cleft lip and / or palate is very important role, as helping the infant to take adequate nutrition safely, as regarded helping in pre and post-operative care of the infant. Furthermore mothers have vital role in post-operative feeding and care <sup>[7]</sup>

According to <sup>[6]</sup>stated that mothers need teaching by demonstrating about surgical wound care, proper feeding techniques and positions. Pediatric nurses should stress on the importance of long term follow up including speech therapy and preventing or correcting dental abnormalities. Furthermore the nurse must instruct mothers to apply annual hearing evaluations because of increasing susceptibility to recurrent otitis media, in addition teaching of infection control measures.

### **1.1 Significance of the Study**

The incidence rate of children suffering from cleft lip and / or palate at Children Hospital in Ain Shams University is approximately (120) cases yearly<sup>[8]</sup> Parents particular mother of the infant with cleft lip and /or palate have an important role for caring and providing good feeding technique pre and post-operative, and serve the infant's needs. Nurses should recognize mother's roles in caring for infant with cleft lip and /or palate and helping them to stimulate the children to have normal milestones, good health, good quality of life and lead to living a near normal life. So from the researcher point of view it is important to conduct this study to shed light on mothers' level of knowledge and practice regarding care of their children with cleft lip and /or cleft palate.

### **1.2 Aim of the study:**

This study aimed to assess mother's knowledge, and practices regarding care of their children with cleft lip and / or cleft palate.

### **1.3 Research Questions:**

1. What are the mothers' level of knowledge and practices regarding care of their children suffering from cleft lip and /or cleft palate?
2. Is there a relation between mothers' level of knowledge and practices and their characteristics?

## **II. Subjects And Methods**

**2.1 Research design:** A descriptive research design was utilized to achieve the aim of this study.

### **2.2 Research setting:**

This study was conducted at in-patient and out-patient pediatric surgical department in children Hospital affiliated to Ain Shams University. While in-patient surgical unit were in the third floor of the hospital, and consist of two chambers, number of nine beds and standing scale. Whereas out-patient unit locate in the first floor, and consists of one chamber, number of three beds, furthermore, there was special place for wound and suture line care.

### **2.3 Subjects:**

A purposive sample of all available children and their accompanying mothers regardless their characteristics were included in the study from the previously mentioned setting, totally 70 children and their mothers.

### **Inclusion criteria were involved in the study:**

- 1- Age group: From one month to two years  
- Excluded children that was free from any mental or physical

### **2.4 Tools of data collection:**

**Two tools were used to collect data as the following:**

#### **Tool (I): Structured interviewing questionnaire sheet:**

It was designed by the researcher in arabic language to suit level of understanding of mothers, after reviewing the relevant literature as El-wasfy, (2009) and Correia, (2017) and revised by supervisors, it included three parts:

**Part A):** Characteristics of the studied mothers, as age, educational level, Job, living residence, and family size.

**Part B):** this part was concerned with mother's knowledge about cleft lip and / or cleft palate such as definition, causes, clinical manifestation, prevention of complication and care.

### **Scoring system:**

Scoring system for knowledge was followed to obtain the percentage of mother's knowledge. Total numbers of questions were (38) questions. The studied mother's answers were compared with a model key answers, where a complete correct answer was scored (2), complete incorrect was scored (1) and incorrect answer was scored (zero) for each area of knowledge. The scores of the items were summed-up and total divided by number of the items, giving a mean score for the items. Regarding the knowledge of the studied sample, accordingly the studied sample knowledge was categorized into two levels:

- Satisfactory ( $\geq 60$ )
- Unsatisfactory ( $< 60$ ).

**Part C):** Reported practices of mothers during care for their children before and after cleft lip and /or cleft palate repair, as feeding and post-operative care.

### **Scoring system:**

The total numbers of questions were (10) questions. The studied mother's answers were compared with a model key answers, where a done answer was scored (2), done incorrect was scored (1), and not done was scored (0). The scores of the items were summed-up and total divided by number of the items, giving a mean score for the items. Regarding the knowledge of the studied sample, accordingly the studied sample practices were categorized into two levels:

- Correctly done ( $\geq 60$ )
- Incorrectly done ( $< 60$ ).

### **Tool II- Children Physical Assessment Sheet:**

This tool was designed by the researcher based on reviewing of literature at El-wasfy, (2009). It was used to assess the general health condition of children suffering from cleft lip and /or cleft palate as:

- Characteristics of the studied children as, age, gender and birth order
- The child's physiological and physical growth as vital signs, weight, types of anomalies, clinical manifestations and history of anomaly.

### **2.5 Pilot Study:**

The pilot study was conducted over a period of one month from the beginning of January 2018 to the end of January 2018. It was conducted on 10% (7) of the studied children and their accompanying mothers to test the applicability, clarity and the efficacy of the study tool and sequence of question to maintain consistency. The necessary modifications (structure of the sentences) were done according to the results of the pilot study and the final form was developed, the studied mothers in the pilot study were excluded from the final study sample.

### **2.6 Field Work:**

The actual field work was carried out over six months started in the beginning of February to the end of August (2018), for data collection, The researcher was available in study setting 2 days weekly (Saturday and Thursday) through the morning shift from 9 am to 3 pm, started by the researcher introducing herself to the mothers, then informing them about the purpose of the study, each mother interviewed individually to fulfill the questioner sheet, the researcher was fill the study tool for illiterate mothers. While educated mothers fill the questionnaire by their self. Questionnaire took 15-30 minutes to be filled, the researcher asked mother if she had any questions to answer them, as regards assessment of the general condition of children by use the physical assessment sheet, the researcher assess the child's weight, skin, ear, nose condition. Furthermore the researcher assess dentition and speech condition in the previously mentioned setting, and assess characteristics of studied children in the previously mentioned setting using the study tool, questionnaire take 10-15 minutes.

### **2.7 Ethical considerations:**

Prior study conduction, ethical approval was obtained from the Scientific Research, Ethical Committee of Faculty of Nursing, Helwan University, the researcher clarified aim of the study to mothers included in the study, and verbal approval was a prerequisite to recruit their children in the study. They were assured also that all the gathered data were used for the research purpose only and the study is harmless. Also, they were allowed to withdraw from the study at any time without giving the reason. Confidentiality of the gathered data and results were secured.

### **2.8 Statistical Design:**

Data collected from the studied sample was revised, coded and entered using the PC. Computerized data entry and statistical analysis were fulfilled using the statistical package for social sciences (SPSS) version 20. Data were presented using descriptive statistics in the form of frequencies and percentages for qualitative variables and measured the standard deviations for quantitative variables. Chi-square test (X<sup>2</sup>) was used for comparisons between qualitative variables.

**Level of significance:**

- P-value <0.05 was considered significant.
- P-value <0.001 was considered as highly significant.
- P-value >0.05 was considered insignificant.

**III. Results.**

Regarding characteristics of the studied mothers, Table (1): this table revealed that the mean age of studied mothers were  $27.54 \pm 5.78$  years, 44.3% of them had bachelor degree, 80% and 62.9 % of them were housewife and from urban area respectively.

Concerning characteristics of the studied children Table (2): this table showed that less than two third (61.4%) of studied children, were male and the mean age of them were  $1.19 \pm 0.23$  years. This table also revealed that 41.4 % of children ranked as the second child.

Regarding mother's total level of knowledge Figure (1) revealed that less than half (54.3%) of the studied mother's had satisfactory total level of knowledge while the remaining 45.7% of them had unsatisfactory knowledge about cleft lip and /or cleft palate.

Figure (2) clarified that more than half of the mother's (55.7%) had an incorrectly level of practice, while the remaining 44.3 % of them had correctly level of practice regarding feeding their children and post-operative care.

Regarding relation between mother's level of knowledge and practices, Table (4) stated that there were statistical significant relations between the studied mother's level of knowledge and their level of practice ( $p < 0.05$ ), where satisfied mother's level of knowledge were having correctly level of total practice towards feeding of their children & post-operative care.

**IV. Discussion**

Regarding the studied mother's characteristics, the findings of the current study revealed that the mean age of studied mothers were  $27.54 \pm 5.78$  years, this study supported with study carried out by [9] at Cairo University in Egypt, which entitled "Assessment of mothers' needs for their infants who have cleft lip and/or palate" which revealed that (72%) aged from 20 < 30.

Regarding the educational level of the studied mothers, the finding of the present study revealed that less than half of them were high educated, these findings were in accordance with the study carried out by [10] entitled "Mothers of Children with Cleft Lip and/or Palate, Perception about Aetiology, Social Reaction and Treatment of Cleft" who found that more than half of the studied mothers were having high school education. This findings also agree with [11] about "Nutritional Status of Children with Cleft Lip, Cleft Palate and Knowledge of their Mothers at Health Care Centres" who found that the majority of mothers in the study were graduates or post- graduates.

According to pre-operative feeding pattern, the findings of this study illustrated that the majority of the studied children were depending on formula bottle feeding and more than half of feeding instruments was long nipple with a wide opening, these findings were similar to a study of [12] entitled "A Pilot study of mothers' breast feeding experiences in infants with cleft lip and/or palate" which found that 90% of the studied children were depending on formula feeding. These results of the current study also disagree with [13], entitled "Retrospective study of breast milk feeding in infants with oral cleft" who found that the majority of feeding experiences of mothers with infants with OFCs depending on exclusively breastfeeding.

Regarding the studied mother's knowledge about feeding type after operation the results of the current study showed that less than two third of mothers had unsatisfactory knowledge about special foods and feeding type after operation respectively, this finding was contradicted with a study illustrated by [14] about "Awareness of feeding, growth and development among mothers of infants with cleft lip and/or palate" which found that more than two thirds of studied mothers were aware of feeding including; breastfeeding, formula-milk feeding, and weaning of infants with a cleft.

Regarding reported practices of the studied mothers about feeding their children with cleft lip and / or cleft palate, the findings of the present study illustrated that more than half of them didn't know the righting position during feeding. The results of the current study also showed that more than two thirds of mothers and the majority of them didn't burping child during and after feeding, and didn't place child in safe and secure right side position or prone position respectively. From the researcher point of view these finding may be due to mothers not taking feeding instructions during follow-up. This finding disagree with a study carried out by [15], about "Assisted breastfeeding technique to improve knowledge, attitude, and practices of mothers with cleft lip- and palate-affected infants: A randomized trial" which found that the majority of studied mothers had successful breastfeeding technique.

Concerning the studied mother's reported level of practices regarding post-operative care, the findings of the current study revealed that more than half of mothers didn't place the child on the side and head on one

hand during feeding. Also the current study illustrated that all mothers observe infection signs of the wound as redness, inflammation and hyperthermia, this finding supported with a study by [16] entitled (Pediatric Nursing, A Case-Based Approach) who revealed that the majority of the mothers were observed the oral cavity frequently for signs of infection, and clean suture lines with normal saline or sterile water.

As regards reported total level of practices regarding feeding of the child, the findings of the current study clarified that more than half of the mother's had unsatisfactory level of practice regarding feeding of the child and post-operative care. This finding is similar to the study of [17] entitled "Oral Health Knowledge, Attitude and Practice of Parents, and Frequency of Cariogenic Food Intake among Their Non Syndrome Cleft Lip with or without Cleft Palate Children in North-east Peninsular Malaysia" which found that all mothers have children with cleft lip and palate that involved in the study had poor health practice about cleft lip and /or cleft palate.

Concerning relation between the studied mother's knowledge and reported practices and their characteristics, the result of the current study showed that there were statistical significant relations between the studied mother's level of knowledge and their characteristics, while mothers that were 20>30 years had satisfactory level of knowledge and mothers were having low level of education and from rural area had unsatisfactory level of knowledge. This finding not consistent with a study discussed by [18], about "Awareness, knowledge and attitudes of Saudi pregnant women towards cleft lip and palate" who found that the total level of knowledge of mothers were high knowledge.

The findings of the present study clarified that there were statistical significant relations between the studied mother's level of reported practice and their characteristics, while mothers that were 20>30 years had a satisfactory level of reported practice. The result of the current study also illustrated that mothers who had low level of education and from rural area, had unsatisfactory level of reported practice. From the researcher point of view, mothers of children with cleft lip and / or cleft palate need to be trained by specialized trained nurse on infant feeding. This finding is disagree with the study of [15] who found that the majority of the mothers had successful breastfeeding.

Regarding the relation between the studied mother's level of knowledge and their level of reported practice, the findings of the present study illustrated that there were statistical significant relations between the studied mother's level of knowledge and their level of reported practice ( $p < 0.05$ ), where satisfactory mother's level of knowledge were having correctly level of reported practice towards feeding of their children & post-operative care. This finding agree with the study [19] about "feeding protocol for mothers having infant with cleft lip and cleft palate" which stated that there were statistical significant differences between knowledge and practice of mothers post feeding protocol at  $P < 0.05$ .

Concerning the studied children physical assessment, the finding of the current study clarified that more than half of children had been diagnosed cleft lip and cleft palate, while less than one fifth of them were having cleft lip and more than one quarter of them were having cleft palate. These findings were similar to the study of [20] entitled "Examining the psychosocial needs of adolescents with craniofacial conditions" who revealed that half of the sample had cleft lip and/or palate.

As regarding the physiological and physical growth of the studied children, the finding of the current study illustrated that about three quarters of children were under-weight. From the researcher point of view, this study finding may be due to the feeding difficulties arisen. This finding agrees with a study of [9] who revealed that 56% of studied children were having weight was not suitable to their age.

According to general appearance of the studied children, the findings of the study revealed that two fifth of children were paler and less than one fifth of them had recurrent ear infection. This finding is similar to study carried out by [21] entitled "Repair of cleft lip and palate a parent's guide" revealed that more than one third of infant who born with a cleft lip and palate is prone to ear infections.

The findings of the present study illustrated that more than three quarters of the studied children had delayed teeth eruption, this finding supported with a study by [22] entitled "Dental Anomalies in Different Types of Cleft Lip and Palate: Is There Any Relation?" who stated that dental anomaly frequency was significantly higher children with cleft, and tooth agenesis was the most common dental anomaly, followed by microdontia and supernumerary tooth.

Finally, according to speech condition of the studied children, the results of the present study showed that about one third of children had hyper-nasality sound, this finding agree with a study of [23] which entitled "Speech and language phenotyping in children with cleft lip and/or palate and their unaffected relatives" who revealed that 37% of children with Sub Mucous Cleft Palate (SMCP) present with speech difficulties. Also this finding agree with a study of [24] entitled "the effect of primary palatal repair on growth in cleft lip and palate patients" who found that more than one quarter of infants had a speech problem in cleft lip and cleft palate.

### V. Conclusion

Based on the finding of the study, the study concluded that less than half of the mother's had unsatisfied level of total knowledge about left lip and /or cleft palate. Also more than half of the mother's had unsatisfactory level of practice regarding feeding of their children and post-operative care. The finding also revealed that there were statistical significant relations between the studied mother's level of knowledge and their level of practices, where satisfactory mother's total level of knowledge were having satisfactory level of total practices towards feeding of their children & post-operative care.

### VI. Recommendations

Based on the study findings, the following recommendations are suggested: Establishing educational programs to improve knowledge and practices of mothers regarding care of their children with cleft and / or cleft palate. Establishing training program for mothers on how to feed their children who suffering from cleft lip and / or cleft palate. Raising awareness of mothers about the importance of follow up care with craniofacial team for promoting their children's health condition. Further researches should be conducted to provide interventional modalities to reduce mother's needs as well as booklets for education about cleft lip and cleft palate.

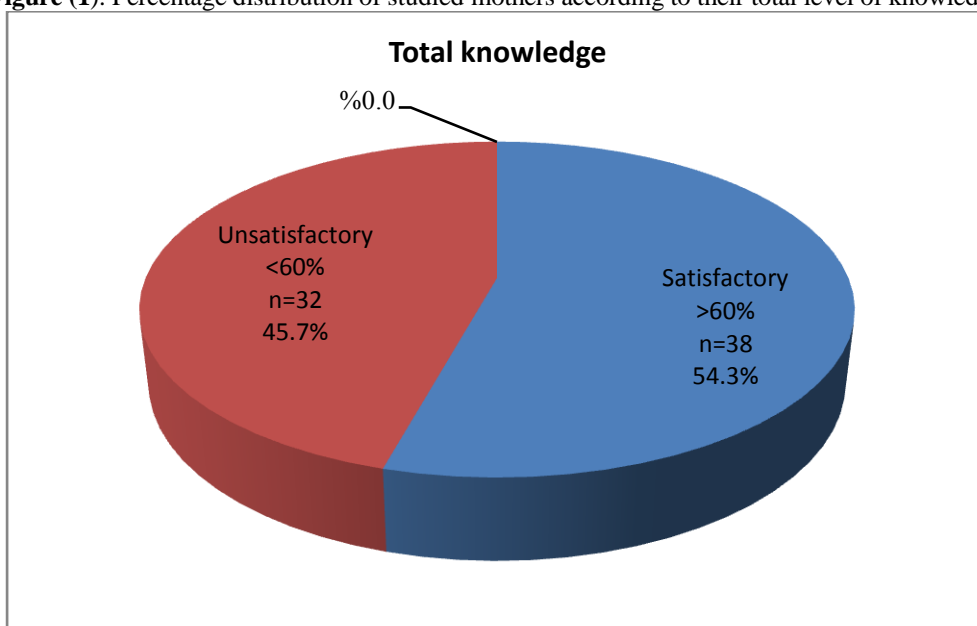
**Table (1):** Number and percentage distribution of studied mothers according to their characteristics (n=70).

Item	No.	%
<b>Age of the mother:</b>		
< 20	2	2.9
20< 30	52	74.3
30 <40	13	18.6
≥ 40	3	4.3
<b>Mean±SD</b>		<b>27.54±5. 78</b>
<b>Mother's level of education:</b>		
Illiterate	8	11.4
Read and write	2	2.9
Primary	3	4.3
Preparatory	7	10.0
Secondary	19	27.1
Bachelor degree	31	<b>44.3</b>
<b>Mother's job:</b>		
Housewife	56	<b>80.0</b>
Working	14	20.0
<b>Residence:</b>		
Rural	26	37.1
Urban	44	<b>62.9</b>

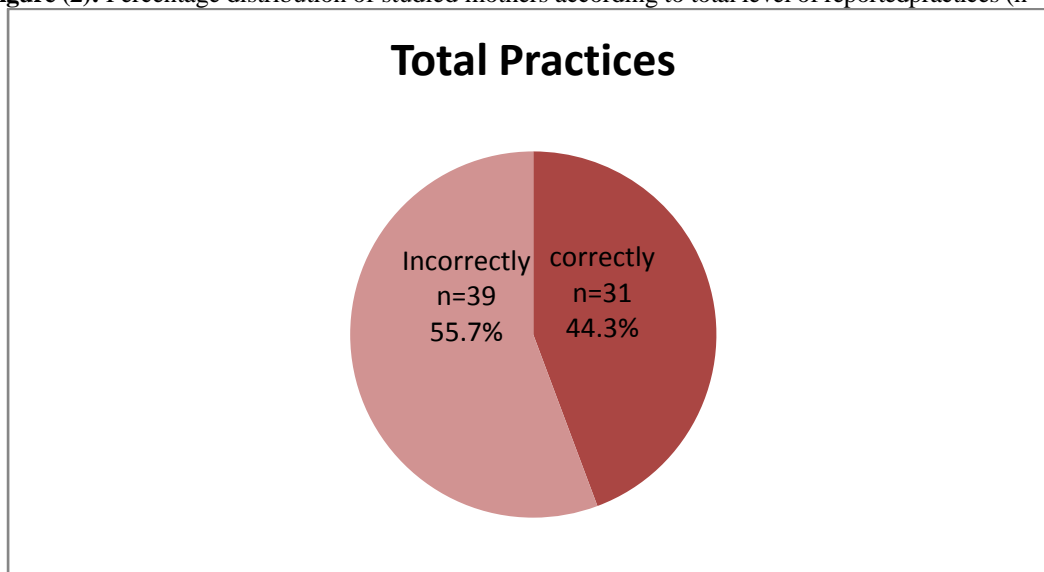
**Table (2):** Number and percentage distribution of studied children according to their characteristics (n=70).

Children Characteristics	No.	%
<b>Gender</b>		
Boys	43	<b>61.4</b>
Girls	27	38.6
<b>Age (years)</b>		
< 1 year	53	<b>75.7</b>
1 ≥ 2 years	17	24.3
<b>Mean±SD</b>		<b>1.19±0.23</b>
<b>Birth order</b>		
First	25	35.7
Second	29	<b>41.4</b>
Third	9	12.9
Forth and more	7	10.0

**Figure (1):** Percentage distribution of studied mothers according to their total level of knowledge.



**Figure (2):** Percentage distribution of studied mothers according to total level of reported practices (n=70).



**Table (4):** Relation between the studied mother's level of knowledge and level of practice towards feeding of their children & post –operative care (n=70).

Total level of practices	Total level of knowledge				Total		Chi-square test	
	Satisfactory >60%		Unsatisfactory <60%				x <sup>2</sup>	p-value
	No.	%	No.	%	No.	%		
Correctly >60%	28	40.0	3	4.3	31	44.3	26.569	<0.001**
Incorrectly <60%	10	14.3	29	41.4	39	55.7		
Total	38	54.3	32	45.7	70	100.0		

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