

## Corelation Of Parents' Profiles Of Children With Late Cleft Repair In Surabaya Cleft Lip And Palate Centre (January 2015 – December 2017)



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### ARTICLE INFO

### ABSTRACT

#### Keywords:

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**Background :** Optimal time of Cleft palate repair is during the 10 to 12 month of age. In this time produce far natural results in terms of speech because it enabled the maturation of scar tissue postoperatively. The soft palate must function properly before the patient starts learning to talk, otherwise speech disorders such as *persistent rhinolalia aperta* might arise. In pediatric patients, the role of parents is very important on adherence to therapy.

**Methods:** This is a cross-sectional study. The first study group was parents of patients who had surgical repair before two years old and the second group was the parents of patients who had repair after two years old. We compared age, monthly income, education level, number of children, and residential distance from Surabaya of the two groups.

**Results :** The data of this study were obtained from the medical records of patients with cleft lip surgery at CLP Center Surabaya in 2015<sup>th</sup> – 2017<sup>th</sup> with total of 358 patients, 172 were female and 186 were male. 52 patients with delayed cleft palate surgery. Patients' parents in both groups were mostly 31-40 years old, were high school graduated, has one child, earned less than 1.5 million rupiah a month, and lived less than 100 kms from Surabaya. From the statistical results, parent's income has the strongest correlation with the patient's age in cleft palate surgery (-2.7). A negative coefficient means that the less parent's income, the more patient likely had delayed cleft palate surgery. While other factors found weak and very weak correlations.

**Conclusions:** The results form patient's parents' interview, concluded that besides economic factors, the lack of information cleft palate treatment is the key factors that contributed to the delay of cleft palate repair. The education level does not affect the delay in cleft palate surgery, because even in high educated parents, sometimes they don't understand the stages of cleft lip and palate treatment. This study emphasized the necessity to educate about the stages of surgery by primary care physicians, to minimize delays.

### INTRODUCTION

Cleft lip and palate is a congenital disorder due to disruption of protrusions on the facial embryo during intra-uterine growth.<sup>1</sup> There are clefts on the lips with or without alveolar and palate cleft Embryologically, this occurs in the first trimester of pregnancy. The incidence of cleft lip and palate is 1-2 per 1000 live births.<sup>2</sup> This number is slightly higher in certain areas such as East Nusa Tenggara, reaching 6-9 per 1000 live births.<sup>3</sup>

Cleft palate repair should be performed at the age of 10 to 12 months. This allows maturation of postoperative scar tissue to soften and optimize speech.<sup>4</sup> Late cleft palate repair may increase the risk of speech function disorders such as *persistent rhinolalia aperta*.

In Surabaya CLP Center, 25% of cleft palate repair are carried out at the age of more than 7 years, 50% at ages 3-7 years, and only 25% are carried out according to the recommended age.<sup>3</sup> There are numerous

factors associated to the late timing of cleft palate repair, among them are the age of parents, parental education, socioeconomic level, number of children in the family, and patient residence. This study aims to analyze the correlation of parents' profile that associated with the delay of cleft palate repair.

**METHOD**

We conducted a retrospective study involving 139 patients who is done the rhinoplasty unilateral operation at Malahayati Hospital from January 2017 to November 2019. Demographic information was recorded such as ratio between pre -

operation and post - operation, gender and age.

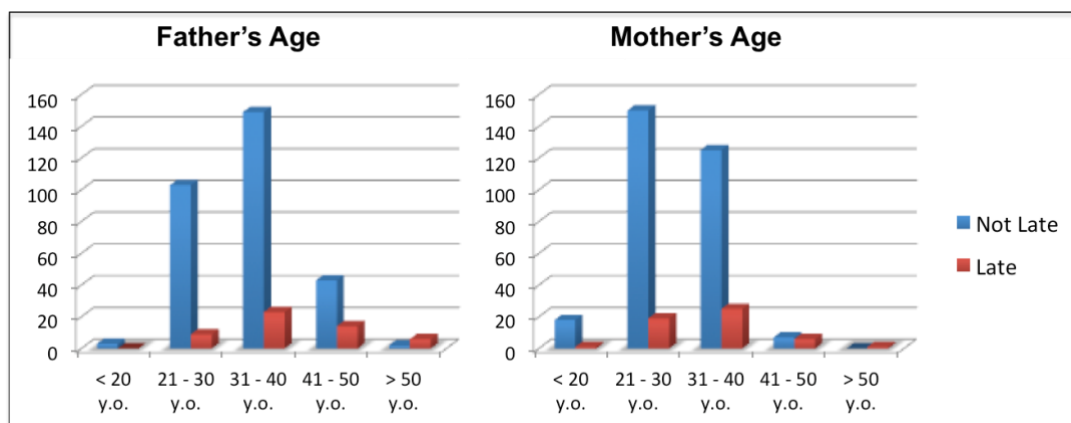
**RESULT**

Data were obtained from the database of patients who underwent cleft palate repair at Surabaya CLP Center from January 1<sup>st</sup>, 2015 - December 31<sup>st</sup>, 2017. A total of 358 patients were included in the study, of which 172 (48,04%) were female and 186 (51,96%) were male. Out of the 358 patients, 52 patients underwent the first cleft palate repair at the age of more than 2 years old. All factors obtained in database were presented in Table 1.

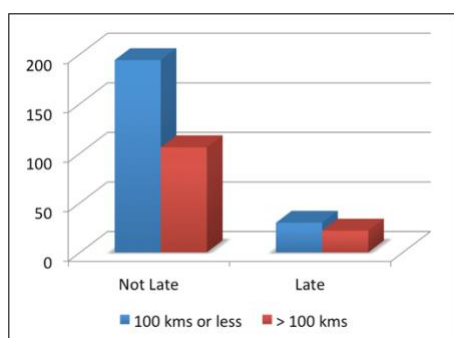
**Table 1. Factors observed in timing of cleft palate repair**

Factors		Not Late		Late	
		Father	Mother	Father	Mother
Age	< 20 y.o.	3	18	-	1
	21 - 30 y.o.	103	150	9	19
	31 - 40 y.o.	149	125	23	25
	41 - 50 y.o.	43	7	14	6
	> 50 y.o.	2	-	6	1
Education	No formal education	7	39	4	6
	Elementary school (SD)	66	46	12	13
	Junior high school (SMP)	58	68	11	12
	High school (SMA)	128	106	23	15
	Higher vocational school	15	15	-	1
	Bachelor	26	26	2	5
Monthly Income	< 1.5 million	236		44	
	1.5 - 2.5 million	35		5	
	2.5 - 3.5 million	17		2	
	> 3.5 million	12		1	
Number of Children	1	141		22	
	2	109		22	
	3	39		6	
	4	9		1	
	>4	2		1	
Residential distance	100 kms or less	194		30	
	> 100 kms	106		22	





**Figure 1 Parents' age and cleft palate repair timing of their children**



**Figure 2 Residential distance from Surabaya**

The average age of the patients' fathers and mothers in both groups is 31-40 years old (Figure 1). Both groups share common characteristic of the parents, those were educational level, monthly income and numbers of children in family. Most were high school graduates, earned less than 1.5 million rupiahs and had one child. The patients in both groups also lived less than 100 kilometres from Surabaya (Figure 2).

Statistical analysis using Chi square was carried out to observe the association between these factors mentioned above to the delay of the cleft palate repair. The fathers' age ( $p = 0.000$ ) and mothers' age ( $p = 0.001$ ) were associated with the delay in cleft palate repair. There was no association between the fathers' education level ( $p = 0.151$ ), mother's education level ( $p = 0.541$ ), number of children in family ( $p = 0.320$ ), and monthly income ( $p = 0.286$ ) and the delay of the surgery. The odds ratio of the residential distance was calculated and it was found that the patients who lived more 100 kilometers away from Surabaya were 1.36 times more

likely to have late cleft palate repair, but this was also insignificant.

Furthermore, 25 interviews were conducted to add perspectives in our analysis. Eleven of the parents interviewed said that they lacked the information about the ideal timing of the cleft palate repair and were informed about Surabaya CLP Center only recently. Ten parents considered the living cost in Surabaya while the children had surgeries. Three parents mentioned having difficulties leaving work and arranging time to go to Surabaya. One mother considered that it was not necessary to have surgery during infancy since she had her own palate repair in adulthood.

## DISCUSSION

There are various factors suspected to have an association with the occurrence of late cleft palate repair. Previous research described that patients who had late cleft palate repair had characteristic of parents as follow: most age of 20-50 years old, graduates of elementary school (SD), and economic level group 1.<sup>5</sup> This finding was different from this study, where in the group of patients who had late cleft palate repair had parents who were mostly aged 31-40 years old and high-school (SMU) graduates, but from the same socioeconomic status.

Analysis showed association between parent's age with late cleft palate repair in children found weak positive correlation, meant the older the parents, the later cleft palate repair was done. This was in contrast to a report from Hertz regarding patient adherence to diabetes treatment,

where the older the patients, the better adherence to control and treatment.<sup>6</sup>

Productive age patients tend to be less adherent to therapy. In Japan, patients of childbearing age were found to be less likely to adhere to treatment.<sup>7</sup> Likewise, in other studies, patients aged 20-40 years also had low levels of adherence.<sup>8</sup> In Singapore, patients aged less than 40 years were found to be less likely to take drugs prescribed in the clinic.<sup>9</sup> Patients in this age range had other priorities in their daily lives. Because of their work and other commitments, they were not able to adhere to the treatment schedule. We found similar pattern where in parents' productive age group, 31-40 years, the children had late cleft palate repair.

The effect of education level on noncompliance in terms of previous studies, has varied results. Several studies found patients with higher education level also have higher levels of adherence.<sup>10,11</sup> While some studies did not find a significant relationship between education level and patient compliance.<sup>12-14</sup> Intuitively, it was expected that patients with a higher level of education should have had better knowledge about the disease and therapy and therefore were expected to be more obedient. However, DiMatteo found that highly educated patients tend not to understand their condition neither believed in the benefits of adherence to their treatment regimen.<sup>15</sup> Other researchers showed that patients with lower levels of education to have better adherence.<sup>16</sup> A UK study group found that patients without formal education qualifications had better adherence to their treatment.<sup>17</sup> It was assumed that patients with lower education level trusted more to doctor's advice. From these results, it seemed that education level was not a good predictor of therapeutic adherence. We found insignificant correlation between parental education and the delay of cleft palate repair to their children.

Cost and income were two interrelated factors and had significant influence on patients' compliance. In this study, parental income had no association to the age of cleft palate repair. Although cleft palate repair was Surabaya CLP Center is free of charge, it was a significant amount of

accommodation cost. A number of studies found that patients without insurance,<sup>18,19</sup> or who have low income were more likely to be non-adherent to treatment.<sup>20-22</sup> Even in the United States, more than one in ten seniors with health insurance, were reportedly not compliant to therapy on cost reason.

This study added valuable information from the interview that the main factors that cause the most delays were the lack of information regarding the phases of the cleft repair, the presence of free surgeries at Surabaya CLP Center. From the interview, we observed that the main factor contributing the delay of the cleft lip repair was access to the surgery itself.

## CONCLUSION

Although we found the association between parental age and the delay of the cleft palate repair in their children, the interview suggests that the problems were access to health care facilities and the lack of information regarding the timing of cleft surgeries. Moreover, access to free health care services and surgery was not available to patients outside Surabaya. This study emphasized the necessity to educate about the stages of surgery by primary care physicians, to minimize delays.

## RECOMMENDATION

We recommended to give more information and disseminate information about the free operation of cleft lip and palate at Surabaya CLP Center. Further in-depth qualitative study should reveal any problems that correlates to delay of the surgery.

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