Sociodemographic Characteristics and Mapping of Patients with Cleft Lip and Palate

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Abstract

The study aimed to determine the sociodemographic characteristics and mapping of patients with cleft lip and palate at YPPCBL or Cleft Centre, Bandung. The descriptive observational study used registration data from YPPCBL Bandung for the 2019–2022 period.

Sociodemographic consisted of the patient's age and sex, diagnosis, mother's age at birth, parents' education level, occupation, income level, and place of residence. A total of 230 data were used for socio-demography analysis and 1725 data were used for descriptive spatial analysis.

Cleft lip and palate (54.8%) were the most diagnosis with the most common was left complete unilateral (30%). Patients first visit at the age of 0-11 months (80%). Mother's age at delivery was 20-24 years (25.7%) with a moderate level of education for fathers (63.5%) and mothers (67.4%). The majority from urban areas (80.4%). The mapping showed patients who visit YPPCBL were spread across 11 provinces in Indonesia, while patients from the social service program were spread across 9 provinces in Indonesia.

The majority of patients are born from parents with a moderate level of education and low income levels. Most of them come from urban areas. The mapping showed that patients of 2019-2022 period are spread across 15 provinces in Indonesia.

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Introduction

Orofacial cleft is the most frequent type of craniofacial anomaly, one of which is cleft lip and palate.[1,2] The occurrence of cleft lip and palate worldwide has a prevalence of 1:700 births, with the highest prevalence in Asian people of 14:10000 births.[1,3] In Indonesia, the cleft lip and palate prevalence is 0.2%.[3] The result of 2018 National Basic Health Research (Riset Kesehatan Dasar [Riskesdas]) reported that the proportion of 24–59 months old children suffering one type of anomaly reached 0.41%, and 0.12% among them are cleft lip and palate patients. The number of cleft lip and palate patients in West Java is discovered to be the highest per 7500 patients in Indonesia, with a percentage of 50.53%.[4] The cleft lip and palate prevalence differs between sex. The male-to-female ratio for cleft lip is 2:1, and for cleft palate is 1:2.[5,6]

Aesthetic alterations are not the only problem caused by cleft lip and palate. This anomaly can also lead the patients to have many functional problems (*e.g.*, difficulties while eating, speaking, and hearing ability) that will hamper their social interactions.[7–9] The conditions will affect patients' confidence, psychological state, and life quality.[1,9,10] The etiologist of cleft lip and palate are based on genetic, epigenetic contributing factors, environmental, and sociodemographic factors.[11,12,13] Some sociodemographic factors involved are maternal education, parents' occupations, geographic area of residence, and sex.[11,14,15] A 2021 study in Guangdong Province of China also reported that the prevalence of cleft lip and palate was higher in the rural than the urban area, with underdeveloped economic conditions, insufficient medical services and uneven distribution of health resources in rural area.[16]

Bandung, the capital city of West Java, has a foundation focused on assisting orofacial anomalies patients—including cleft lip and palate

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patients—called Yayasan Pembina Penderita Celah Bibir dan Langit-Langit (YPPCBL) or Cleft Centre Bandung. YPPCBL is a legal and independent non-profit social organization that supports patients with cleft lip and palate from low-income families. YPPCBL has supported over ±19,300 cleft lip and palate patients, especially in West Java and generally in Indonesia.[17]

The amount of study concerning orofacial anomalies in low and middle-income countries (LMIC), including Indonesia, is limited.[18] A previous study suggested doing a deeper study of sociodemographic characteristics and mapping of patients with cleft lip and palate in Indonesia, particularly in West Java and the surrounding area.[19] The information regarding the incidence of cleft lip and palate and sociodemographic factors as the region-based aetiology is essential to be known so that the planning and implementation of community health intervention in preventing cleft lip and palate can be effective.[1] Approaches based on sociodemographic and geographic risk factors can provide an overview of data in the field and the areas with high risk factors can be seen, so it is expected to help in analysis and problem solving. Therefore, the authors were interested in conducting a study about sociodemographic characteristics and mapping patients with cleft lip and palate in YPPCBL Bandung using secondary data from the registration data of YPPCBL Bandung.

Materials and methods

This study is a descriptive observational study. The sampling technique used purposive sampling. The research data came from Yayasan Pembina Penderita Celah Bibir dan Langit-langit (YPPCBL) or Cleft Centre Bandung. The study was conducted in February-March 2023. This research has received ethical approval from the Research Ethics Commission of Universitas Padjadjaran Bandung with number 161 / UN6. KEP/EC/2023.

This research procedure begins by taking secondary data, namely YPPCBL Bandung registration data for the 2019-2022 period. Patients registered at the foundation consist of patients who come directly to foundation address in the city of Bandung and who come from social service activities in various regions in Indonesia. Both categories of patients are included in mapping cleft lip and palate cases with the aim of obtaining the distribution of cases in various regions in Indonesia. From the registration data, 738 data of patients who came and were registered at YPPCBL Bandung and 1013 data of patients who were registered as YPPCBL Bandung social service patients for the 2019-2022 period.

The next stage is a selection process based on inclusion criteria. The inclusion criteria in this study are cleft lip and palate patients registered at YPPCBL Bandung for the 2019-2022 period, for sociodemographic analysis: have complete sociodemographic data, and for descriptive spatial analysis: all patient domicile data (at least district or city) both who come to YPPCBL Bandung and social service patients in various regions in Indonesia for the 2019-2022 period. The exclusion criteria in this study are illegible registration data.

The population in this study is divided into two categories that will be analyzed separately, namely the group of cleft lip and palate patients who come and are registered at YPPCBL Bandung and the group of cleft lip and palate patients who are registered as social service patients. Data from both groups were then selected according to inclusion criteria and then analyzed. Data that met the criteria for sociodemographic analysis were obtained, namely 230 data from the group of cleft lip and palate patients who came and registered at YPPCBL Bandung; for descriptive spatial analysis, namely 712 data from the group of cleft lip and palate patients who came and registered at YPPCBL Bandung and 1013 data from the group of cleft lip and palate patients who were registered as social service patients. Sociodemographic analysis was performed using Microsoft Excel while descriptive spatial analysis was performed using QGIS Desktop version 3.28.2.

Results

Table 1 shows the characteristics of all cleft lip and palate patients who came and were registered at YPPCBL Bandung for the 2019-2022 period, totalling 738 patients. Meanwhile, Table 2 shows the characteristics of all cleft lip and palate patients who came and were registered at YPPCBL Bandung for the 2019-

2022 period and met the inclusion criteria, totalling 230 patients. Table 1 and 2 both shows that most patients are male and the majority of patients come to YPPCBL for treatment in the age range of 0-11 months. When analysed based on the type of cleft, both table shows that the most patients were diagnosed with cleft lip and palate, and based on the location of the cleft, the most patients were diagnosed with a left complete unilateral cleft lip and palate. Other diagnosis are incomplete data so they cannot be included in the diagnosis classification based on the type or location of the cleft. The age categories for Table 1 and 2 is adjusted to 2018 National Basic Health Research (RISKESDAS) age categories.

Characteristic	Number (n)	Percentage (%)
Sex		
Female	307	42%
Male	431	58%
Missing	0	0%
Age when came to YPPCBL for treatment		
0-11 months	423	57.3%
12-59 months	207	28%
5-9 years	37	5.1%
10-14 years	17	2.3%
15 or more, years	32	4.3%
Missing	22	3%
Diagnosis by cleft type		
Cleft lip	153	20.7%
Cleft lip and palate	290	39.3%
Cleft palate	219	29.7%
Others	59	8%
Missing	17	2.3%
Diagnosis by cleft location		
Cleft lip:		
Right complete unilateral cleft lip	16	2.2%
Left complete unilateral cleft lip	22	3%
Right incomplete unilateral cleft lip	37	5%
Left incomplete unilateral cleft lip	58	7.9%
Complete bilateral cleft lip	5	0.7%
Incomplete bilateral cleft lip	12	1.6%
Cleft palate:		
Right complete unilateral cleft palate	38	5.1%
Left complete unilateral cleft palate	60	8.1%
Right incomplete unilateral cleft palate	2	0.3%
Left incomplete unilateral cleft palate	10	1.4%
Complete bilateral cleft palate	29	3.9%
Incomplete bilateral cleft palate	2	0.3%
Cleft lip and palate:		
Right complete unilateral cleft lip	61	8.3%
Left complete unilateral cleft lip	141	19.1%
Right incomplete unilateral cleft lip	8	1%
Left incomplete unilateral cleft lip	19	2.6%
Complete bilateral cleft lip	82	11.1%
Incomplete bilateral cleft lip	6	0.8%
Others	114	15.4%
Missing	16	2.2%

Table 1. Characteristics of cleft lip and palate patients of YPPCBL Bandung for the 2019-2022 period (n=738).

Table 3 shows that most cleft lip and palate patients were born to mothers aged 20-24 years and 25-29 years. The majority of education levels of fathers and mothers with cleft lip and palate is moderately educated or equivalent to graduating from junior high school and high school. Majority of the patient's parents' jobs are fathers as labourers/drivers and non-working mothers. The categorization of parents' income levels in Table 3 is based on the categories determined by YPPCBL Bandung. It was found that the income level of the majority of patients' fathers ranged from Rp1,000,000–Rp2,000,000/month, while the mother's income was Rp0–Rp1,000,000/month. As many as 185 patients (80.4%) came from urban areas.

Characteristic	Number (n)	Percentage (%)
Sex		
Female	89	38.7%
Male	141	61.3%
Age when came to YPPCBL for treatment		
0-11 months	184	80%
12-59 months	36	15.7%
5-9 years	3	1.3%
10-14 years	3	1.3%
15 or more, years	4	1.7%
Diagnosis by cleft type		
Cleft lip	52	22.6%
Cleft lip and palate	126	54.8%
Cleft palate	37	16%
Others	15	6.6%
Diagnosis by cleft location		
Cleft lip:		
Right complete unilateral cleft lip	8	3.5%
Left complete unilateral cleft lip	8	3.5%
Right incomplete unilateral cleft lip	11	4.8%
Left incomplete unilateral cleft lip	16	7%
Complete bilateral cleft lip	5	2.2%
Incomplete bilateral cleft lip	1	0.4%
Cleft palate: :		
Right complete unilateral cleft palate	3	1.3%
Left complete unilateral cleft palate	6	2.6%
Right incomplete unilateral cleft palate	0	0%
Left incomplete unilateral cleft palate	0	0%
Complete bilateral cleft palate	4	1.7%
Incomplete bilateral cleft palate	3	1.3%
Cleft lip and palate:		
Right complete unilateral cleft lip	29	12.6%
Left complete unilateral cleft lip	69	30%
Right incomplete unilateral cleft lip	5	2.2%
Left incomplete unilateral cleft lip	8	3.5%
Complete bilateral cleft lip	32	13.8%
Incomplete bilateral cleft lip	6	2.6%
Others	16	7%

Table 2. Characteristics of cleft lip and palate patients of YPPCBL Bandung for the 2019-2022 period whom met inclusion criteria (n = 230).

Mapping of all patient domiciles has been carried out by grouping the coordinate points of each patient's address based on the district/ city. The mapping is divided into two, namely mapping of 712 data of cleft lip and palate patients who came to YPPCBL Bandung (Figure 1) and 1013 data of cleft lip and palate patients registered as

YPPCBL Bandung social service patients (Figure 2).

Characteristic	Number (n)	Percentage (%)
Age of the mother at childbirth		
10–14 years	1	0.4%
15–19 years	16	7%
20–24 years	59	25.7%
25–29 years	59	25.7%
30–34 years	48	20.9%
35–39 years	44	19.1%
40–44 years	2	0.8%
45–49 years	1	0.4%
Parental education level		
Lower education (elementary school)	69	30%
Moderate education (junior and senior high school)	146	63.5%
Higher education (diploma, undergraduate, and postgraduate)	15	6.5%
Maternal education level		
Lower education (elementary school)	61	26.5%
Moderate education (junior and senior high school)	155	67.4%
Higher education (diploma, undergraduate, and postgraduate)	14	6.1%
Father's occupation		
Civil servant/army/Police/public sectors or government	4	1.7%
Entrepreneur	60	26%
Private sector	42	18.3%
Farmer	9	3.9%
Labors/ drivers	114	49.7%
Others	1	0.4%
Mother's occupation		
Unemployed or housewife	207	90%
Entrepreneur	2	0.8%
Private sector	12	5.3%
Farmer	3	1.3%
Labors/ drivers/ housekeeper	5	2.2%
Others	1	0.4%
Father's income level		
IDR 0-1,000,000/month	50	21.7%
IDR1,000,000–2,000,000/month	104	45.2%
IDR2,000,000–3.000.000/month	46	20%
>IDR3,000,000–4,000,000/month	20	8.7%
IDR4,000,000–5,000,000/month	6	2.7%
>IDR5,000,000/month	4	1.7%
Mother's income level		
IDR 0-1,000,000/month	216	94%
IDR1,000,000–2,000,000/month	3	1.3%
IDR2,000,000–3.000.000/month	5	2.2%
>IDR3,000,000–4,000,000/month	4	1.7%
IDR4,000,000–5,000,000/month	2	0.8%
Residence		
Urban	185	80.4%
Rural	45	19.6%

Table 3. Characteristics of parent's sociodemographic whom met the inclusion criteria for the 2019-2022 period (n=230).

Figure 1 shows the distribution of all cases of cleft lip and palate patients who came to YPPCBL for the period 2019-2022 (n=712). The darker the color of the district/city, the more cases in the area. Cleft lip and palate patients who come to YPPCBL Bandung are spread across 11 provinces in Indonesia, namely DKI Jakarta, West Java, Banten, Bengkulu, Central Java, East Java, West Kalimantan, Riau Islands, South Sulawesi, North Sumatra, and South Sumatra. The mapping results (Figure 1) show that the highest number of cases is in Garut Regency with 140 cases.

The results of the descriptive spatial analysis in the form of case distribution from 1013 cleft lip and palate patient data of YPPCBL Bandung social service patients for the 2019-2022 period who met the inclusion criteria are listed in Figure 2. Patients with cleft lip and palate YPPCBL Bandung social service patients are spread across 9 provinces in Indonesia, namely Bali, West Java, Central Java, Jambi, East Java, West Kalimantan, NTB, NTT, and South Sumatra. The mapping results (Figure 2) showed that the location of the social service that netted the most cases of cleft lip and palate was Mataram City, NTB with 429 patients. It is characterized by the darkest color of the region.

Discussion

The results of the study in Tables 1 and 2 showed that the number of patients with male more than the female. This is in line with the results of research conducted at the University of Muhammadiyah Malang in 2015 which stated that the incidence of cleft lips, cleft palate, and cleft lip and palate is more common in men when compared to women.[20] The reason why cleft lip or cleft lip and palate is more common in men cannot be explained because there is not much literature to confirm it.[21]

Table 2 shows that in the period 2019-2022, patients aged 0-11 months are the most likely age who come to YPPCBL for treatment (80%). The American Cleft Palate-Craniofacial Association (ACPA) states that cleft patients should be treated immediately at the age of 12 months and cleft palate treatment should be given when the patient is 18 months old.[22] This means that the majority of cleft lip and palate patients at YPPCBL Bandung have been treated in a timely manner. Treatment of cleft lip and palate must be done in a timely manner, as too early treatment of cleft will cause changes in craniofacial growth, while late treatment of cleft will hinder the patient's speech development.[22]

The results of the study in Table 2 showed that cleft lip and palate were the most common diagnosis found from patients who came and were registered at YPPCBL Bandung 2019-2022, which was 126 people (54.8%). Judging from the location of the gap, the most diagnosis in patients are cleft lip and left complete unilateral palate as many as 69 people (30%). This is in line with research conducted in Turkey which states that unilateral fissures are more prevalent on the left side.[23] It is not known

exactly why the gap on the left side is found so much. A study conducted on animals' states that at the time of development the left side of the palatal shelves take longer to rotate until it reaches a horizontal position compared to the right side. Research shows that the pressure of the left carotid artery is lower than the pressure of the internal carotid artery on the right side and the development of the left carotid artery is longer than the right so that blood perfusion to the left is lower.[21]

The results of the study in Table 3 showed that most patients were born to mothers aged 20-34 years (72.3%). This is contrary to the results of research conducted by Pamungkas et al., in 2021 which stated that mothers aged <20 years and > 35 years have a risk of giving birth to congenital defects of 4.82 times than mothers who give birth at the age of 20-35 years.[24] This is in accordance with a study conducted by Abdelazim et al., in 2017 which states that abnormalities in infants can be associated with advanced maternal age.[25]

Table 3 shows that the education level of fathers and mothers with cleft lip and palate is the most moderate education, namely junior and high school. This is in line with research conducted in Brazil which states that a high prevalence of cleft lip is found in children born to mothers who have only studied for 7 years. Low maternal education can have an impact on health and nutritional fulfilment in early pregnancy.[11] The incidence of cleft lip and palate is associated with the consumption of folic acid and multivitamins during pregnancy. The results of a study in Mexico stated that the main risk associated with the incidence of cleft lip and palate is not taking folic acid and multivitamins during pregnancy.[26]

The work and income of the patient's parents from Table 3 are mostly as non-working and non-income housewives and fathers as labourers/drivers with incomes ranging from IDR 1,000,000–2,000,000/month. Epidemiological studies in the Philippines report that the lower the socioeconomic status of a family, the higher the risk of experiencing cleft lip and palate. This is because family socioeconomic status is closely related to prenatal care including the fulfilment of maternal nutrition during pregnancy.[15,27,28]

Table 3 shows that as many as 185 patients (80.4%) lived in urban areas. This is contrary to the results of research conducted in Guangdong, China which states that the prevalence of cleft lip and palate patients in rural areas is higher than in urban areas. It is not yet known why this happens, but research conducted by Lee et al., in 2021 states that environmental factors such as exposure to air pollution and toxic chemicals in pregnant women can increase the risk of congenital abnormalities in children.[29] This is also supported by the results of research conducted by Rao et al., who stated that air pollution is consistently associated with an increased risk of orofacial cleft anomalies.[30]

Figure 1 shows that cleft lip and palate patients are found in almost all regencies/cities located in West Java Province. The highest cases were in Garut Regency (140 cases) followed by Bandung Regency (120 cases) and Bandung City (105 cases). It is not yet known exactly why this happens, but research suggests that variations in distance to each health service also have an impact on transportation costs, thus determining the health care facility chosen.[31] Research conducted in Brazil also states that public knowledge of the service system in a health care facility contributes to the use of health care facilities.[32] This is also in line with the mapping results in Figure 1 which shows that cleft lip and palate patients who come to YPPCBL Bandung from South Sumatra and West Kalimantan Provinces only come from one district/city.

Figure 2 shows the results of mapping carried out on 1013 patients with cleft lip and palate patients of YPPCBL Bandung social service for the 2019-2022 period. This social service is carried out in various regions in Indonesia, such as NTB, NTT, West Java, Bali, Central Java, West Kalimantan, East Java, Jambi, and South Sumatra. The location of the social service that netted the most cases of cleft lip and palate was Mataram City, NTB with 429 patients. All cases netted by the social service carried out in Mataram City are an accumulation of the number of patients from the social service held as many as 15 visits during the 2019-2022 period. The choice of location and time of social service is not based on the results of specific research, but YPPCBL explained that the location and time of social service are adjusted to hospitals that are willing to cooperate with YPPCBL Bandung. Further research is needed to determine the factors behind the selection of social service

locations, as well as to determine the epidemiology of cleft lip and palate at the location.

Some limitations were found in the study. First, there is limited information on patient registration data regarding craniofacial abnormalities other than cleft lip and palate so that patient diagnosis cannot be distinguished based on syndromic and non-syndromic clefts. Second, there is incomplete data on sociodemographic characteristics in social service patients, so they are not included in sociodemographic analysis. Third, the majority of patients who come to YPPCBL Bandung come from low socioeconomic levels, so researchers can only see a picture of that level. Fourth, the use of secondary data is a limitation for researchers to explore other variables related to the purpose of this study. It is recommended to conduct further searches using primary data collection methods to obtain more in-depth information about the sociodemographic characteristics of cleft lip and palate patients at YPPCBL Bandung, and conduct research that investigating the underlying mechanisms connecting sociodemographic factors and cleft lip and palate occurrence. This allows a more complete assessment of other variables related to the sociodemographic of patients so as to provide a broader and comprehensive picture. It is necessary to optimize the collection and recording of registration data at YPPCBL Bandung so that the recorded data can be more complete. In addition, calibration or standardization methods of input patient registration data can be done so that the data stored is valid and does not cause bias.

The advantage of this study is the mapping of cleft lip and palate patients registered at YPPCBL Bandung in the 2019-2022 period. This can provide an overview of the spread or distribution area of cleft lip and palate cases in Indonesia from the secondary data, so that it can be the basis for designing and implementing effective public health interventions for the prevention of cleft lip and palate in areas that have high number of cases of cleft lip and palate, and also basis for designing risk factors study in some areas based on the mapping. Form the results, we can evaluate from the existing healthcare policies, resource and healthcare facility and access, also the planning for intervention minimum such as health promotion and preventive program according to the risk and the pattern of number of cases.

Conclusions

The results of this study discovered that the majority of cleft lip and palate patients who came to YPPCBL Bandung in 2019–2022 were males and visited YPPCBL Bandung at the optimal age for receiving treatment. The sociodemographic characteristics of most patients were born to moderate-educated and low-income parents. More patients came from urban regions than rural regions. The mapping results show that cleft lip and palate patients who came to YPPCBL Bandung and cleft lip and palate patients of YPPCBL Bandung's social service in 2019–2022 spread across 15 provinces in Indonesia. This condition shows that the spread of cleft lip and palate cases in Indonesia is still large and requires attention from stakeholder, dental public health towards health promotion and prevention as well as clinical treatment for the patient. The socioeconomic status of parents, limited location and access to health services are still obstacles. Therefore, to be able to improve these conditions requires collaboration and support from various related parties.

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Declaration of Interest

The authors report no conflict of interest.

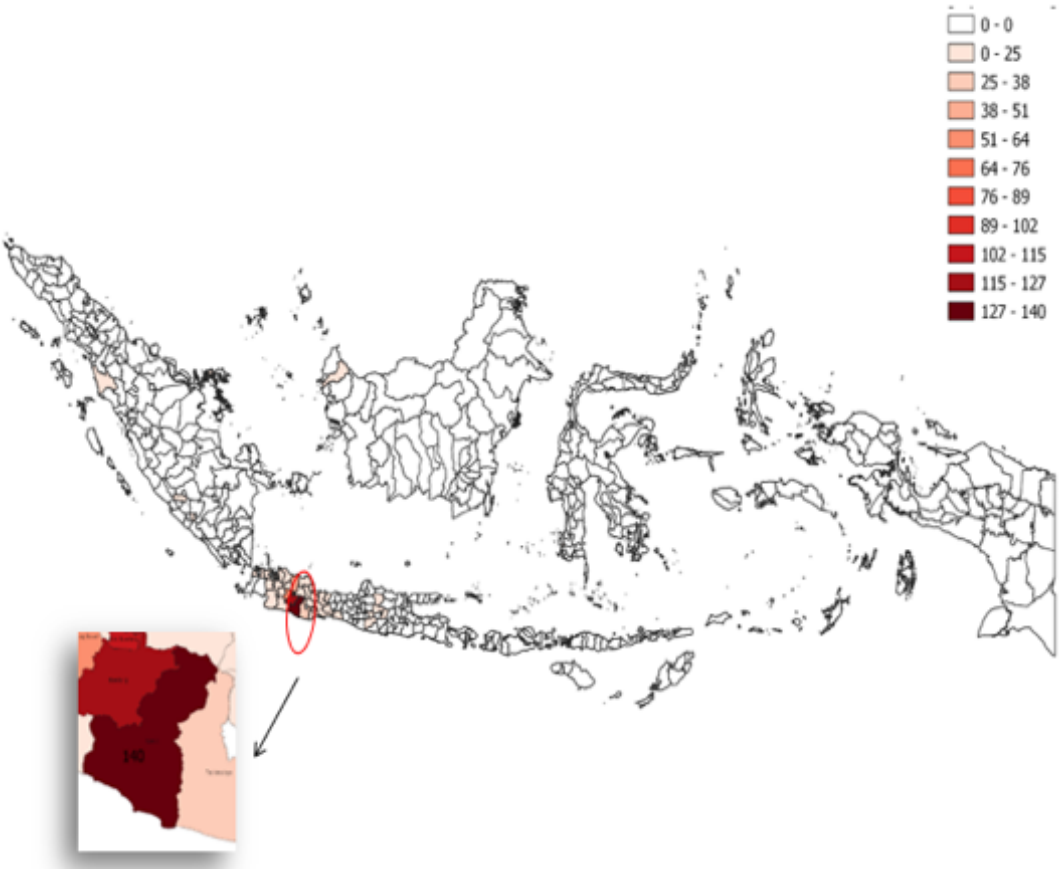

Figure 1. Map of the distribution of cleft lip and palate sufferers who come to YPPCBL Bandung in Indonesia (n=712).

Figure 2. Map of the distribution of cleft lip and palate patients of social service patients in Indonesia.

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