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Age at primary surgery among orofacial cleft individuals in Indonesia

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Abstract

Objectives: To observe the age at primary cleft surgery among charity organizations such as Smile Train in helping Indonesia manage patients with OFC.

Materials and Methods: A retrospective analysis of medical records was conducted to identify patients with orofacial clefts who underwent primary surgery between 2001 and 2021. The age at the time of surgery was recorded for each patient. Descriptive statistics were used to analyse the data and determine the average age at primary surgery.

Results: In the period between 2001 and 2021, a total of 34 239 individuals in Indonesia underwent primary lip surgery, while 16 768 individuals received primary palatal surgery, as recorded in the Smile Train database. Notably, a significant proportion of these surgeries were classified as delayed primary repairs. Approximately 65.3% of primary lip surgeries were performed beyond the recommended timeline of 6 months of age, indicating a delay in the surgical intervention. Similarly, 67% of primary palatal surgeries were also delayed, occurring after the recommended timeline of 18 months of life.

Conclusions: This study provides insights into the age at primary surgery among individuals with orofacial clefts in Indonesia. The findings highlight the need for timely intervention and the importance of considering individualized treatment plans based on the specific type of orofacial cleft. Further research is warranted to explore factors influencing the age at primary surgery and their impact on treatment outcomes and long-term functional outcomes in this population.

KEYWORDS
age, cleft lip, cleft palate, health services, surgery

Abbreviations: CL, isolated Cleft Lip; CLP, Cleft Lip and Palate; CP, isolated Cleft Palate; LMIC, Low-and-Middle-Income Countries; OFC, Orofacial Clefts; ST, Smile Train; UHC, Universal Health Coverage; WHO, World Health Organization.

1 | INTRODUCTION

Birth defects contributed to 17% of newborn deaths and 11% of under-five deaths in Indonesia.[1] The most common birth defect in the craniofacial area is orofacial cleft (OFC).[2] OFC are morphological abnormalities that affect the upper lip and/or the roof of the mouth. OFC malformation which occurs during early foetal development may present as a cleft lip only (CL), cleft palate only (CP) or cleft lip and palate (CLP) and its prevalence may vary among different populations and regions.[3]

Unlike the data from high-income countries (HIC), the study conducted in 2017, which examined information from cleft lip and palate (CLP) registries, revealed disparities in low- and middle-income countries (LMICs). This study synthesized that in LMICs, approximately 1 in every 730 children is born with OFC.[4] A study which mapped the OFC research in indexed literature found inequalities in terms of number of publications produced in HIC and LMIC.[5] These discrepancies may be attributed to a lack of research expertise and insufficient emphasis from governmental research funders on prioritizing OFC research.

Primary surgeries were defined as the first surgeries performed on any anatomical region of the cleft. Whereas secondary surgeries were defined as the subsequent surgeries performed after the primary surgery on the same anatomical region of the cleft.[6] Primary cleft lip surgery is crucial for restoring the normal anatomy and function of the lip, correcting nasal deformity and reconstructing the floor of the nose to achieve proper alignment of the gum line, whereas primary cleft palate surgery is essential to close the palatal defect and establishing a properly functioning velopharyngeal mechanism to facilitate normal speech production.[7,8] Delay in reconstructive cleft lip surgery leads to detrimental effects on physical appearance, speech development, feeding, dental and psychological conditions.[9] For cleft palate, delay in palatal surgical repair caused delayed speech therapy, revision procedures for velopharyngeal insufficiency and proper otologic care.[10]

As per the guidelines set by the United Kingdom and the American Cleft Palate-Craniofacial Association (ACPA), it is recommended that cleft lip repair be conducted before the age of 6 months. Similarly, cleft palate repair is advised to be performed before the age of 12 months in the United Kingdom and before the age of 18 months according to the ACPA.[11,12] Timely cleft surgery is important to address functional impairments, facilitate speech development, improve psychological well-being, maintain dental health and promote proper facial growth and development. Early intervention significantly enhances the quality of life for individuals with cleft lip and palate.

Currently, birth defects are not registered by the national health system uniformly across Indonesia. The aim of this study is to observe the age at primary cleft surgery among children with OFC in Indonesia using a dataset derived from non-profit organization in the management of patients with OFC in Indonesia.

2 | MATERIALS AND METHODS

The data set included 49 366 retrospective surgical records of individuals who underwent primary cleft surgery financially funded by Smile Train between 2001 and 2021. These surgeries were conducted by 90 Smile Train partner surgeons in 328 treatment centres across 34 provinces in Indonesia. The data were extracted through the Smile Train Express database (STX), an electronic health record (EHR) system developed specifically as a billing system and quality control tool for all institutions partnered with Smile Train.[13]

This is a retrospective study involving surgical records, and all data were anonymized before our access. Informed consent for data participation in research was obtained from all participants and/or their legal guardians by Smile Train. Ethical procedure was exempted by the Research Ethics Committee Universitas Padjadjaran (717/UN6.KEP/EC/2023). We have taken measures to ensure that all experiments were conducted in accordance with relevant guidelines and regulations.

Preliminary search resulted in 49 366 surgical treatments containing the targeted variables—birth date, sex, province of origin, partner hospital, type of surgery and date of primary surgery—was analysed using descriptive statistics. The spreadsheet was transferred to IBM SPSS Statistics for Windows version 26 for descriptive analysis (IBM Corp).

This study collected data on the crude birth rate and total population in Indonesia from 1984 to 2021 to estimate the total number of births (World Bank, 2023a, 2023b). This number was then divided by the cleft prevalence in LMICs as reported by Kadir et al., 2017 of one in 730 live births to estimate the approximate cleft incidence in Indonesia. This set of estimated birth incidence of cleft infants was then compared with the annual number of primary cleft repairs in Indonesia.

3 | RESULTS

Primary lip surgery may be a single primary lip repair or may be combined with other repairs. Primary palatal repair is a single primary palatal repair or may be combined with other repairs. The 49 366 OFC primary surgical records included in the study, were divided into two groups of primary lip surgery and primary palatal surgery for further analysis (Table 1). In our study, we observed a total of 27 842 cases of unilateral cleft lip and 6397 cases of bilateral cleft lip. These findings indicate a higher prevalence of unilateral cleft lip compared to bilateral cleft lip in the studied population. A total of 1641 records were identified where individuals underwent primary lip and primary palatal surgery in a single procedure. These surgical records contributed to the total number of both groups, whereas 34 239 individuals received primary lip surgery, while 16 768 individuals underwent primary palatal surgery.

The distribution of frequencies for primary lip repair and primary palatal repair was analysed by gender. Among the cases of primary lip repair, 36.8% were females, accounting for 12 604 cases, while males accounted for 63.2% with 21 635 cases. For primary palatal repair, 39.1% were females (6550 cases) and 60.9% were males (10 218 cases). The frequencies of both primary lip and primary palatal surgery demonstrated a higher prevalence among males.

The inclusion of geographical regions revealed the prominence of specific provinces in primary orofacial cleft surgeries (Figure 1). The top six contributors in Indonesia were identified as follows: West Java, with a total of 8931 surgeries; East Java, with 6792 surgeries; North Sumatera, with 6425 surgeries; Central Java, with 5373 surgeries; Jakarta, with 4369 surgeries and Aceh, with 3169 surgeries.

Figure 2 presents an annual comparison between the estimated number of cleft incidence and the number of primary lip and palatal repairs conducted in Indonesia. The estimates for the number of cleft babies were calculated based on data from the World Bank and the prevalence of orofacial clefts in LMICs. The number of primary lip and palatal repairs represents the actual surgical procedures performed in Indonesia. The chart reveals a gap between the operated OFC babies and the estimated number of babies born with OFC in Indonesia.

TABLE 1 Distribution of frequencies grouped by the type of primary cleft repair.

Types of surgery	*n*
Primary lip surgery[a]	34 239
Unilateral = 27 842	
Bilateral = 6397	
Primary palatal surgery[b]	16 768
Total (included)	51 007
Primary lip and primary palatal surgery in one sitting	1641
(34 239 + 16 768) - 1641 = 49 366	

[a]Contributed by CL and CLP.
[b]Contributed by isolated CP and CLP.

Among the primary cleft lip repair cases included in the analysis, it was found that only 34.7% of the cases adhered to the recommended timeline for surgery, which is within 6 months of age (Table 2). This indicates that a significant proportion of individuals with cleft lip experienced delays in receiving surgical intervention beyond the recommended time frame. The mean age at primary cleft lip repair was calculated to be 54.74 months, with a median age of 11 months. The standard deviation for the age at surgery was 106.57 months, indicating a wide variation in the timing of primary cleft lip repair among the cases analysed. Among the cases included in the analysis, it was identified that 25 individuals who underwent primary lip repair were between 65 and 80 years old.

In the analysis of primary cleft palate repair, it was observed that only 33.0% of the cases adhered to the recommended timeline for surgery, which is under 18 months of age (Table 2). Most of the cases experienced delays in receiving the surgery. The mean age at the time of primary palate repair was found to be 60.23 months, with a median age of 26 months. The standard deviation was calculated to be 75.64 months, indicating a considerable variation in the age at which the surgery was performed. The maximum recorded age for primary palate repair was 87.7 years old, which represented the only patient in the elderly age group who received primary palatal repair.

Figure 3 displays a stacked bar chart illustrating the distribution of primary cleft surgeries categorized by age group. The x-axis represents the proportion of surgical volume, while the y-axis represents the types of primary surgeries. Each bar is divided into

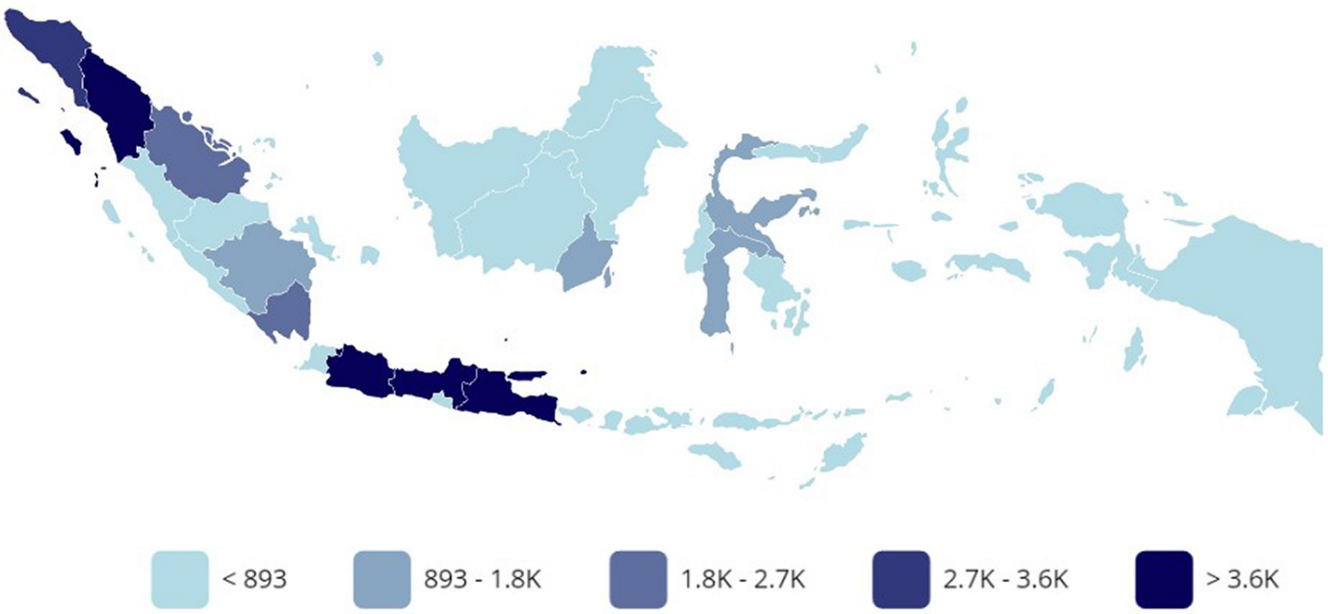

FIGURE 1 Heat map illustrating the distribution of primary cleft surgeries across provinces in Indonesia.

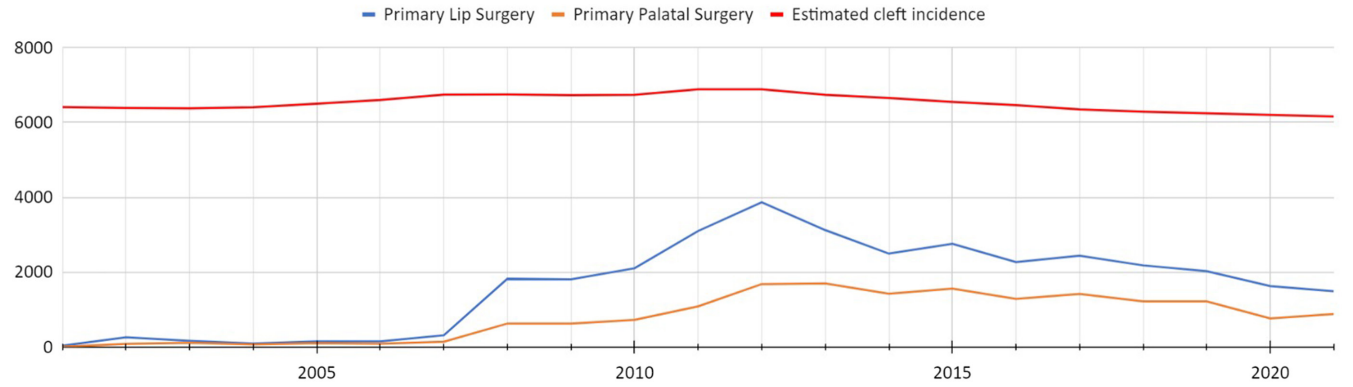

FIGURE 2 Annual comparison between the estimated number of cleft incidence and the number of primary lip and palatal repairs in Indonesia.

TABLE 2 Timing of primary lip and palatal surgery in Indonesia.

Age at primary lip surgery (mo)		Age group	*n*	%
n	34239	0-6 mo	11520	34.7
Mean	54.74	7-12 mo	6762	19.7
Median	11	13-24 mo	4317	12.6
Std. Deviation	106.57	25-60 mo	4088	11.9
Minimum	0	>5 y	7552	22.1
Maximum	967	Total	34239	100
Age at primary palatal surgery (mo)		**Age group**	***n***	**%**
n	16768	<9 mo	486	2.9
Mean	60.23	9-18 mo	5050	30.1
Median	26	19-24 mo	2377	14.2
Std. Deviation	75.64	25-60 mo	4108	24.5
Minimum	0	>5 y	4747	28.3
Maximum	1053	Total	16768	100

coloured segments, representing specific age ranges within each type of primary surgery. This chart provides a visual representation of the age distribution of primary cleft surgeries, offering insights into the volume of surgeries. Notably, the red-shaded segments indicate a delay in primary cleft surgery, accounting for approximately 70% of both primary lip and primary palatal surgeries.

4 | DISCUSSION

Only a limited number of studies have provided information on cleft subtypes and the distribution by sex in epidemiological reports on LMICs.[4] Previous studies have shown a male predominance in cases of OFC.[2] While this study did not specifically examine the sex distribution of OFC incidence, but rather focused on the number of primary lip and palatal surgeries, the observed sex distribution in this study aligns with previous findings, highlighting a higher proportion of males.

Figure 2 depicts the estimated birth incidence of OFC in Indonesia by combining data on crude birth rate,[14] total population in Indonesia,[15] and the prevalence of OFC in LMICs.[4] The trend in OFC incidence is then compared to the number of primary OFC surgeries recorded by Smile Train. The graph shows discrepancies between the lines representing the number of OFC cases, which can be categorized into three groups. The first group consists of individuals who received surgical treatment outside of Smile Train's coverage, such as those covered by Indonesia's UHC or other humanitarian organizations. The second group includes individuals who have not received surgical treatment and are at risk of mortality due to the burden of living with an untreated cleft. The third group comprises individuals who have not received surgical treatment but have survived and reached a certain age. These disparities highlight the varied outcomes and challenges faced by individuals with OFC in terms of access to timely surgical intervention. The figure displays a significant disparity between the number of OFC cases operated on and the overall incidence of OFC. This discrepancy emphasizes the need to improve access to care, raise awareness about the importance of timely cleft surgeries and address the barriers that prevent individuals from receiving appropriate treatment. Efforts should be made to bridge this gap and ensure that all individuals with OFC have access to the necessary care and interventions. Unoperated OFC escalates the risk of infant mortality, attributed to issues like malnutrition, respiratory disorders and neglect effects. These challenges should ideally be averted with timely care from proper healthcare facilities, yet this remains a persistent challenge in Indonesia, as evidenced by the ongoing necessity for surgical missions.

4.1 | Importance of timeliness primary surgery

OFC is not considered to be a life-threatening condition requiring emergency surgery. Nonetheless, the analysis of records of primary cleft operations conducted in Indonesia showed that over 60% of individuals with clefts received delayed primary reconstructive surgery. These findings underscore the importance of timely intervention for

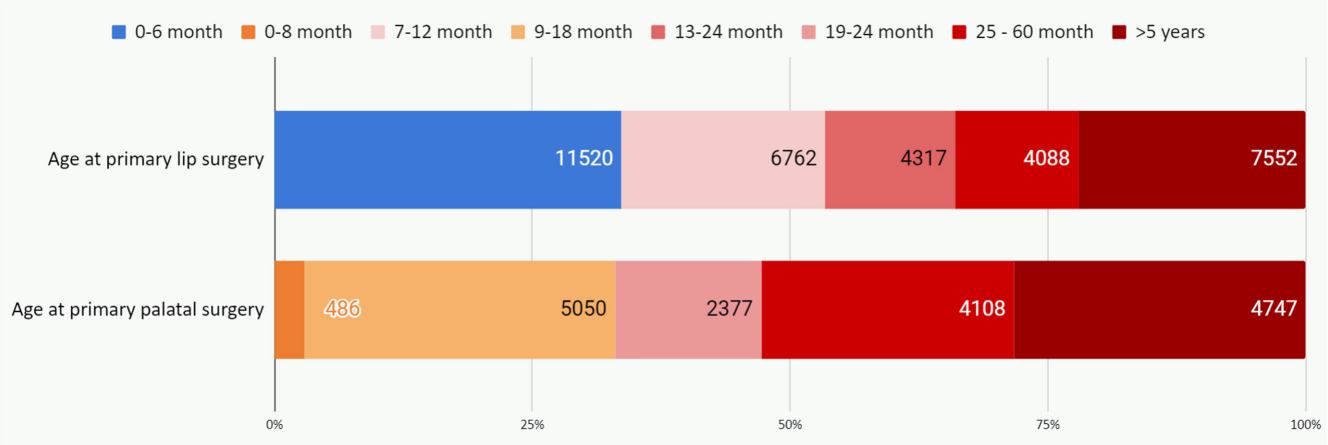

FIGURE 3 Stacked bar chart of primary cleft surgery based on age groups.

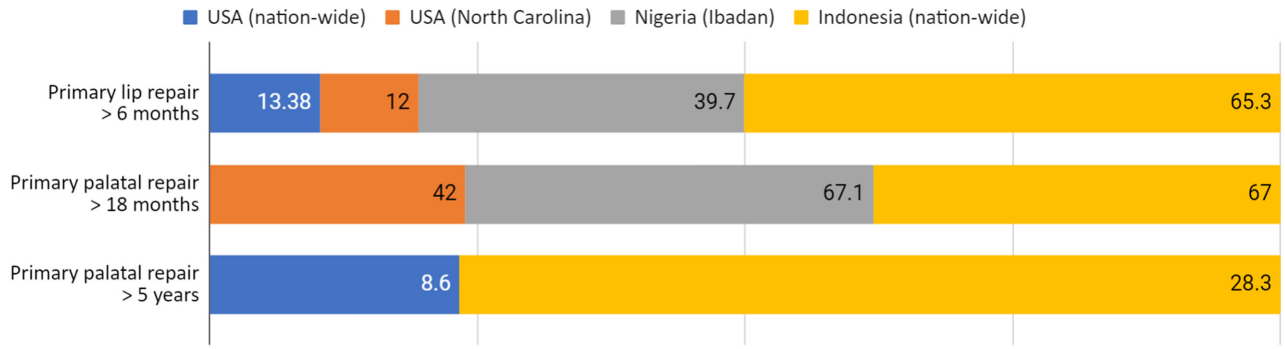

FIGURE 4 Percentage of delayed primary cleft surgeries among countries.

cleft palate repair, as delays can impact speech development and other functional outcomes. These factors collectively influence an individual's ability to achieve significant milestones in life. Children who have not undergone repair for cleft lip and/or palate also face a substantial risk of mortality.[16] There was a significant decrease in estimated survival rates for individuals with an unrepaired cleft, with less than 25% surviving beyond the age of 5. In contrast, patients who received timely surgical care for their clefts had survival rates similar to those unaffected by the condition.[2] Efforts should be made to ensure that children receive the appropriate surgical treatment within the recommended timeline to optimize their long-term outcomes.

Specifically for primary palatal surgery, the timing has been a subject of controversy. The debate centres around whether early surgery would yield better speech outcomes but potentially hinder maxillary growth, or if delaying palatal closure would improve maxillary growth but impair speech formation. In Europe and the United States, the recommended age for primary palatal repair is within 12 months. To shed light on the favourable timing of primary surgery for cleft palate, randomized controlled trials are currently underway comparing the outcomes of surgery at 6 months versus 12 months.[8,17] These studies aim to provide valuable insights into the optimal timing for achieving the best results in cleft palate repair.

4.2 | Comparison of timeliness at primary surgery between countries

Figure 4 compares the proportion of delayed primary cleft surgeries among countries based on previous studies.[6,7,18] Regarding delayed primary lip surgery beyond 6 months of age, this study revealed the highest contribution to surgical delay (65.3%). In terms of delayed primary palatal repair beyond 18 months of age, the results from Indonesia (67%) were comparable to those of the Nigerian study (67.1%). Furthermore, a significant proportion of primary palatal repairs that were significantly delayed beyond 5 years old were still observed in Indonesia (28.3%) compared to the United States (8.6%). This study highlights the significant proportion of delayed primary cleft surgeries in Indonesia, particularly for lip and palatal repairs.

4.3 | Surgical delay

When analysing the data on the timing of primary OFC surgeries, it becomes evident that a substantial proportion of both primary lip and primary palatal surgeries were performed beyond

the recommended timeline. This study identified 1641 cases of one-stage cleft lip and palate repair. These individuals comprised late-presenting patients with cleft lip and palate (CLP), necessitating immediate surgical intervention. Despite the inherent challenges of prolonged surgical duration and technical complexity, this form of cleft surgery was deemed both feasible and safe for implementation.

Furthermore, it was observed that a number of primary lip surgeries were conducted during the adolescent age. This is concerning as it highlights the burden of disease and the potential impact on the quality of life for individuals who undergo these surgeries at a later stage.

The considerable delay in the age of primary cleft repair is performed, highlighting the significant backlog of untreated cases of cleft lip or cleft palate. Among different income categories, low-income countries had the highest average age of presentation, which gradually decreased in low middle-income, upper middle-income and high-income countries.[19] This trend underscores the association between the level of economic development and challenges related to accessibility and availability of a vital yet elective paediatric surgical procedure.

An HIC study found that there could be several factors contributing to children facing delays in primary cleft surgeries such as syndromic diagnosis, comorbidity and participation in approved research.[7] The obstacles to accessing cleft care vary geographically and differ among different patient.[20] Research indicates a significant association between national income and delayed access to primary cleft palate surgery. Specifically, in low- and lower-middle-income countries, there is a 70 percent higher likelihood of late surgery for every $1000 decrease in Gross Domestic Product per capita.[21] The phenomenon of unrepaired cleft found in middle-aged children, adolescents and adults, as observed in this study, aligns with a previous study conducted in Nigeria. This occurrence can potentially be attributed to factors such as poverty, lack of awareness and limited accessibility to adequate healthcare facilities.[22] It should be noted that no attempt has been made by this study to quantify the number of unrepaired clefts.

4.4 | Geographic distribution

The distribution of cleft surgeries among provinces in Indonesia was found to be disproportionate. Six provinces have consistently accounted for the highest volume of cleft surgeries over the past two decades. This disparity could be attributed to factors such as the presence of a larger number of surgeons in those provinces, the establishment of specialized cleft treatment centres, or a higher population leading to a greater prevalence of cleft lip and palate cases. These provinces have demonstrated commendable efforts in addressing the needs of individuals with cleft conditions through surgical interventions, thereby making significant contributions to the overall number of surgeries performed across the country.

4.5 | Limitations and strengths of the study

This study acknowledged several limitations that readers should take into account when interpreting the data. First, the raw data used in this study originated from the usage of administrative and billing data for patient selection rather than the birth defect surveillance system which means that they may not accurately reflect the actual numbers. Furthermore, the data collected for this study consisted of a combination of surgical activity data from hospitals in developed cities and surgical missions conducted in rural areas for humanitarian purposes.

A notable strength of this study is that the STX database serves as an extensive EHR, which compensates for the absence of a comprehensive birth defect registration system in Indonesia. This study is a cross-sectional study utilizing secondary data from the archive of Smile Train Express, a billing software for surgical treatments. Previous studies within the 5 years time-frame have explored the STX database to gain insight of OFC in multiple LMIC settings,[13,23–26] or single LMIC settings such as Nigeria.[6] These studies have demonstrated the significant role of a humanitarian organization in enhancing access to care for those in need while also increasing research volume for treatment outcome and epidemiology fields.

STX has become the most extensive repository of OFC data in Indonesia. The utilization of such a vast database allows for a more comprehensive and representative sample of individuals with birth defects, providing a valuable resource for researchers and policymakers. The inclusion of a diverse range of patients from different regions and backgrounds enhances the generalizability and robustness of the findings. This wealth of data offers a unique opportunity to investigate patterns and trends related to birth defects in an Indonesian population that would otherwise be challenging to study.

4.6 | Critical importance of a nationwide birth defect surveillance system

There are significant data deficiencies in the birth defect registries of low- and middle-income countries (LMICs), leading to substantial gaps in cleft epidemiology.[4] This study highlights the urgent need for a comprehensive birth defect surveillance system in Indonesia that meets specific criteria. These criteria include the ability to gather comprehensive data on birth defects, facilitate robust research, use standardized nomenclatures for international data comparison, be accessible and easy to use for input in all birthing centres across Indonesia, and have uniform and sustainable input from relevant human resources. While these criteria may seem challenging to achieve, they are not impossible with strong partnerships between stakeholders such as the World Health Organization (WHO), government agencies, researchers and humanitarian organizations. Additionally, the successful development of a birth defect registry system in neighbouring LMICs serves as an example and can guide the efforts in Indonesia.

Several LMICs have successfully established birth defect registry systems, providing encouragement to Indonesia that building

a robust birth defect surveillance system is feasible. However, it is important to recognize that Indonesia faces unique challenges compared to other LMICs, primarily due to its vast geographic region and complex archipelagic terrain. These factors have posed obstacles to the implementation of a comprehensive health registry system across all areas of Indonesia. Before implementing a uniform and sustainable birth defect registry system, it is crucial to ensure the availability of necessary infrastructure, including the construction and organization of birthing centres. Addressing these infrastructure challenges remains an ongoing process for Indonesia.

According to the data, the number of primary lip surgeries was twice as high as the number of primary palatal surgeries. However, it is important to interpret this finding with caution, as it does not necessarily mean that the incidence of cleft lip is twice as high as that of cleft palate. The timing of cleft lip repair is typically earlier than that of cleft palate repair, with lip repair recommended within the first 6 months of life. The same infants were being double counted in both primary lip surgery and primary palatal surgery whether they underwent those surgeries in one sitting and in two separate surgeries.

This study, represents a lower estimate of the actual number of cleft surgeries performed in Indonesia. In addition to the cleft treatment funded by Smile Train, there are other cleft centres that offer treatments through Indonesia's Universal Health Coverage (Social Security Administrator for Health/BPJS Kesehatan) and receive support from domestic and international non-governmental organizations. However, this study does not account for the number of unrepaired OFC cases and associated mortality, which may contribute to the existing gap. This aspect should be addressed in future research.

Future research using this set of raw data should explore the phenotypic spectrum of CLP and distribution, which may provide further understanding regarding CLP in Indonesia. Furthermore, the current dataset also highlights hospital-based and mission surgeries. This sets the stage for a significant objective in the next study, which aims to assess the disparities between these two types of surgical sites. Apart from the above discussion focusing on facilitating timely care, this study would also like to mention the imperative prevention effort and improving quality of care. In addition, the next agenda should focus on improved ascertainment and better access to care as a necessary component for timely cleft repair to avoid complications caused by delayed intervention.

5 | CONCLUSIONS

The current study offers an overview of the timing of cleft lip and cleft palate repair in Indonesia. Barriers to timeliness of primary cleft surgery need to be addressed to give children with clefts in Indonesia the chance to survive and develop to their full potential. Efforts to protect the most disadvantaged children, including those born with a cleft, are paramount to achieve significant progress towards the health targets of SDG 3 aligned to the principle of UHC and concomitantly reduce health inequalities within countries by 2030.

AUTHOR CONTRIBUTIONS

ES and PM carried out study design. PD was also involved in data collection. ES and AR also carried out data analysis. ES, AR, PD and PM were involved in manuscript preparation.

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CONFLICT OF INTEREST STATEMENT

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

DATA AVAILABILITY STATEMENT

Due to restrictions imposed by third-party regulations, the data from the Smile Train database cannot be included as a Supporting Information file. However, interested parties can request the data directly from the Smile Train data manager at stxadmin@smiletrain.org. The authors anticipate that Smile Train will provide access to the data for fair and ethical use in research purposes. It is important to note that the authors did not have any special access or request privileges for the data.

ETHICS STATEMENT

Ethical procedure was exempted by the Research Ethics Committee Universitas Padjadjaran (717/UN6.KEP/EC/2023).

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