

## Research Article

## The Use of Social Media Among Parents of Cleft Lip and Palate Patients for Patient Education

Prasetyanugraheni Kreshanti,\* Alita Indania, Valencia J. Martin,  
Margareth I. Anggraeni, Jasmine A. Wibowo

Department of Surgery, Faculty of Medicine, Universitas Indonesia –  
dr. Cipto Mangunkusumo Hospital, Jakarta

\*Corresponding author: Prasetyanugraheni@ui.ac.id  
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### Abstract

Parents' adherence to cleft lip and palate treatment plans is essential to ensure a satisfactory outcome. With the ongoing development of communications technology, social media has become an integral component in medical practice. It is now a platform of communication and information that facilitates medical professionals and parents to provide better care for cleft lip and palate patients. The aim of the study is to investigate the use of social media among parents of CLP patients and their preferable social media of choice for patient education. This is a descriptive study conducted through an online and offline survey amongst 108 parents of CLP patients from January to June of 2019. WhatsApp, Facebook, Instagram, and YouTube are social media platforms that the respondents heavily use. WhatsApp (76,1%) is the most common tool to seek cleft lip and palate information, followed by websites and Facebook. Information that respondents often inquire include feeding technique, post-surgical wound treatment, and funding for the treatments. Overall, respondents believed that information acquired from social media is reliable. Aversion towards social media in obtaining information was revolving around inaccuracy (69,1%) and reliability (39%). Social media has become a fundamental aspect in the treatment of cleft lip and palate. Physicians should consider social media and be actively involved in ensuring the dissemination of accurate and reliable information to patients. WhatsApp is a suitable tool to serve as a platform to provide patient education. A chatbot powered by artificial intelligence can be further developed and investigated for future use.

**Keywords:** cleft lip, cleft palate, social media, education, mobile applications.

## Penggunaan Media Sosial pada Orang Tua Penderita Bibir Sumbing dan Lelangit untuk Pendidikan Pasien

### Abstrak

Kepatuhan orang tua terhadap rencana perawatan celah bibir dan langit-langit sangat penting untuk memastikan hasil yang memuaskan. Dengan perkembangan teknologi komunikasi, media sosial telah menjadi komponen integral dalam praktik medis. Saat ini terdapat platform komunikasi dan informasi yang memfasilitasi para profesional medis dan orang tua untuk memberikan perawatan yang lebih baik untuk pasien celah bibir dan langit-langit. Untuk mengetahui penggunaan media sosial di antara orang tua pasien bibir dan lelangit sumbing dan media sosial pilihan mereka untuk pendidikan pasien. Studi deskriptif yang dilakukan melalui survei daring dan luring yang melibatkan 108 orang tua pasien bibir dan lelangit sumbing dari Januari sampai Juni 2019. WhatsApp, Facebook, Instagram, dan YouTube merupakan platform media sosial yang paling banyak digunakan responden. WhatsApp (76,1%) merupakan alat paling digunakan untuk mencari informasi celah bibir dan langit-langit, diikuti oleh situs web dan Facebook. Informasi yang sering dibutuhkan responden antara lain teknik pemberian makan, perawatan luka pasca-operasi, dan dana perawatan. Secara keseluruhan, responden menyatakan bahwa informasi yang diperoleh dari media sosial dapat dipercaya. Keengganan terhadap media sosial dalam memperoleh informasi berkisar pada ketidak-akuratan (69,1%) dan keandalan (39%). Media sosial telah menjadi aspek fundamental dalam perawatan celah bibir dan langit-langit. Dokter harus mempertimbangkan media sosial dan terlibat aktif dalam memastikan penyebaran informasi yang akurat dan dapat diandalkan kepada pasien. WhatsApp adalah alat yang cocok untuk berfungsi sebagai platform dalam memberikan pendidikan pasien. Chatbot yang didukung kecerdasan buatan dapat dikembangkan dan diteliti lebih lanjut untuk digunakan di masa mendatang.

**Kata kunci:** bibir sumbing, celah langit-langit, media sosial, edukasi, aplikasi mobile.

## Introduction

According to World Health Organization (WHO), the prevalence at birth of orofacial cleft varies worldwide, ranging from 3.4–22.9 per 10,000 births for cleft lip with or without cleft palate, and 1.3–25.3 per 10,000 births for cleft palate alone.<sup>1</sup> In Indonesia, the prevalence of cleft lip with or without cleft palate is 0.08%.<sup>2</sup> There are 196,7 million internet users in Indonesia in 2020,<sup>3</sup> of which 91% utilize it to access social media.<sup>4</sup> The most accessed social media are YouTube and WhatsApp.<sup>5</sup> Sixty-one percent of American adults seek information online, which affects their health-related decisions.<sup>6</sup> Information technology has been widely used in providing patient education in many other conditions.<sup>7–9</sup> In plastic surgery, most information present in the media are regarding aesthetic procedures. However, in Indonesia, social media usage to spread specific patient-related information is just starting and hasn't been much utilized.

Cleft lip and palate (CLP) treatment comprise of various procedures involving multidisciplinary health professions. The treatment duration extends for years thus may significantly affect the psychosocial aspect of the patients. Another aspect of the treatment that is often overlooked is parents' adherence, which is pivotal to ensure treatment continuity, thus resulting in a satisfactory outcome. Considering a significant fraction of Indonesian internet and social media users, this gives rise to the opportunity to take advantage of social media as an adjunct tool in cleft lip and palate treatment. Social media can be used as a tool to disseminate information to patients, educate patients about treatment milestones; therefore adhere to the planned scheme of therapy. Patients will be more likely to access information if it is spread through their preferred social media platform. Social media can support and empower patients as they become more knowledgeable.<sup>10</sup>

This study will assist healthcare professionals, especially plastic surgeons, to utilize the dissemination of information through media platforms and put it into practice. This study aims to explore patients' preferable social media applications to access patient's education regarding cleft lip and palate treatment.

## Methods

This descriptive study was conducted amongst 108 parents of cleft lip and palate patients. The

questions were made by a craniofacial consultant with years of clinical experience and peer-reviewed internally. The survey was administered online and offline between January and June 2019. Offline participants were obtained from patients visiting a tertiary national referral hospital in Indonesia, during the same period. Meanwhile, online participants filled a questionnaire disseminated in an Indonesian cleft community WhatsApp group, *Komunitas Satu Senyum*. The online survey is spread through Google Forms and the results are presented in Microsoft Excel format. After attaining verbal consent, we asked the parents' of patients to fill a survey that consists of patient data and 15 multiple choice questions in Indonesian language.

Patients were enquired to describe their activity level on the six popular social media networks: WhatsApp, Facebook, Instagram, YouTube, Twitter, and websites. Subsequent questions were concerning the usage of social media to obtain information about cleft lip and palate, participation in social media groups for patients with the same condition, duration of participation, the type of information attained, which type of information patients found most appealing, whether the information obtained was helpful or accurate compared to direct consultation with a specialist. Finally, we evaluated obstacles, reliability, and advantages of online information regarding cleft lip and palate for the patients.

Inclusion criteria includes patients with cleft lip or palate diagnosis, has seen a doctor regarding their condition, and have access to internet and social media. Data are presented as frequency, percentage, and means with associated standard deviations.

## Results

Questionnaires were completed by 108 respondents, 77.8% of which completed the questionnaire through an online platform. On average, the age of parent respondents were 32 year old (SD  $\pm$  5.3) mothers 34 year old (SD  $\pm$  5.38) fathers. More than half (65.74%) of the mothers were housewives while 52.78% of the fathers work in private sectors. Among them, only 30,56% of the respondents had known their child's CLP diagnosis prior to birth on average at the gestational age of 28 weeks (SD  $\pm$  7.0). Majority of the patients (97.22%) have no sibling(s) with cleft lip and/or palate. Respondents' characteristics are presented in Table 1.

Table 1. Respondents' Characteristic

Characteristics	n	%
Mother's Age		
<25 year	9	8.33
26-30 year	35	32.41
31-35 year	36	33.33
36-40 year	21	19.44
>40 year	7	6.48
Father's Age		
<25 year	2	1.85
26-30 year	32	29.63
31-35 year	30	27.78
36-40 year	29	26.85
>40 year	15	13.89
Mother's Occupation		
Medical Field Occupation (Midwife, Medical Doctor, Dentist)	5	4.63
Civil Servant	7	6.48
Private Employee	18	16.67
Teacher/Lecturer	4	3.70
Housewife	71	65.74
Others (Psychologist, Entrepreneur)	3	2.78
Father's Occupation		
Private Employee	57	52.78
Civil Servant	12	11.11
Labor	4	3.70
Entrepreneur	22	20.37
Teacher	3	2.78
Medical Doctor	2	1.85
Other (Engineer, Lawyer, Security, Farmer, Student)	6	5.56
Number of Children		
1	37	34.26
2	46	42.59
3	18	16.67
4	7	6.48
Patient's Age		
<1 year	39	36.11
1-2 year	25	23.15
2-3 year	17	15.74
3-4 year	10	9.26
4-5 year	7	6.48
>5 year	10	9.26
Prenatal Diagnosis of Cleft Lip and/or Palate		
Yes	33	30.56
First-trimester	1	0.93
Second-trimester	8	7.41
Third-trimester	21	19.44
No	75	69.44
Sibling(s) with Cleft Lip and/or Palate		
Yes	2	1.85
No	105	97.22

Fig. 1 represents respondents' engagement to various types of social media. WhatsApp was reported to have the highest engagement

and is used more than once a day by 84 out of 108 respondents, followed by Facebook (51 respondents) and Instagram (50 respondents).

In contrast, Twitter had the lowest engagement with only 21 respondents reported its usage. The social media platform used to acquire information about cleft lip and/or palate is illustrated in Fig. 2. In accordance with engagement, majority of the respondents (82 respondents) utilized WhatsApp, followed by Website and Facebook.

With multitude types of information regarding cleft lip and/or palate, we specify the types of information acquired through social media (Fig. 3). Information regarding care of surgical wound was the most frequently inquired information from social media, ahead of information concerning

feeding technique and pre- and postoperative images. More than 97% of respondents agreed that information obtained from social media are helpful and 65.1% thought that these are accurate if compared with consultation with a plastic surgeon. Fears of using social media to obtain information were revolving around inaccuracy (69.1%) and reliability (39%). Most respondents (94%) didn't experience anything unpleasant while joining CLP social media group. Some respondents provided commentary citing that the information may not apply to all patients and not evidence based (Fig. 4).

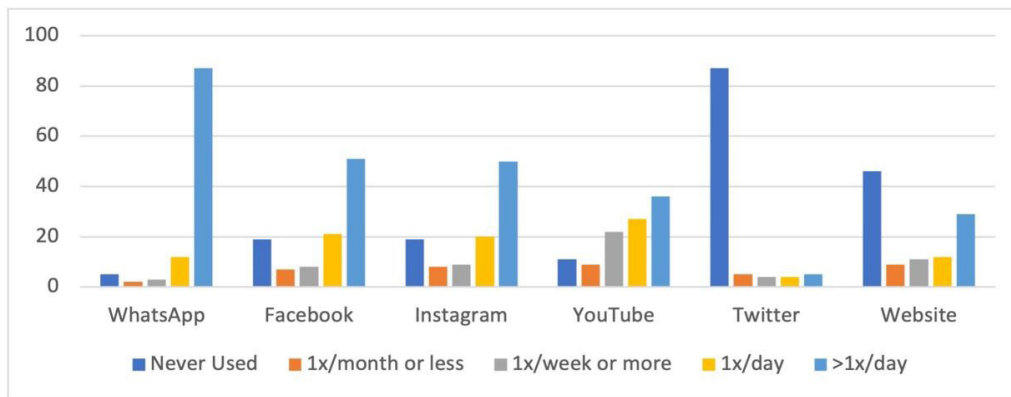


Figure 1. Social Media Engagement

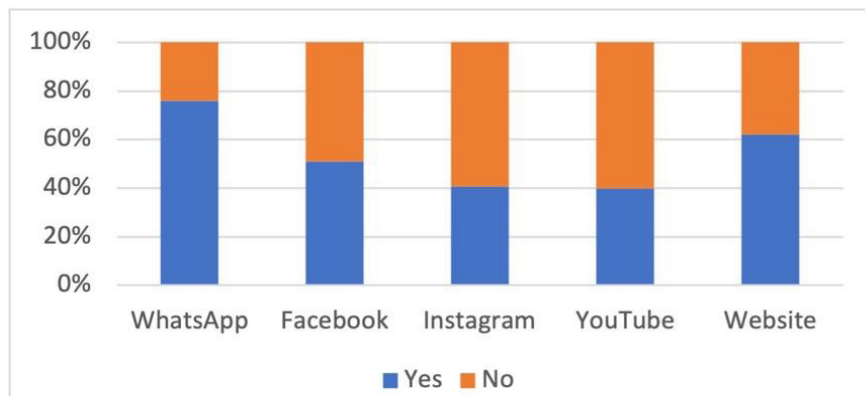


Figure 2. Social Media Utilized for Information about Cleft Lip and/or Palate

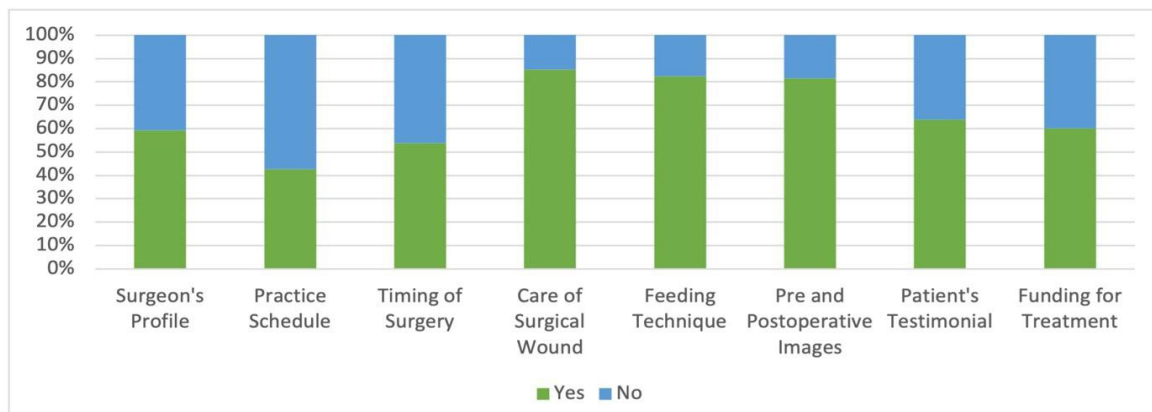


Figure 3. Type of Information

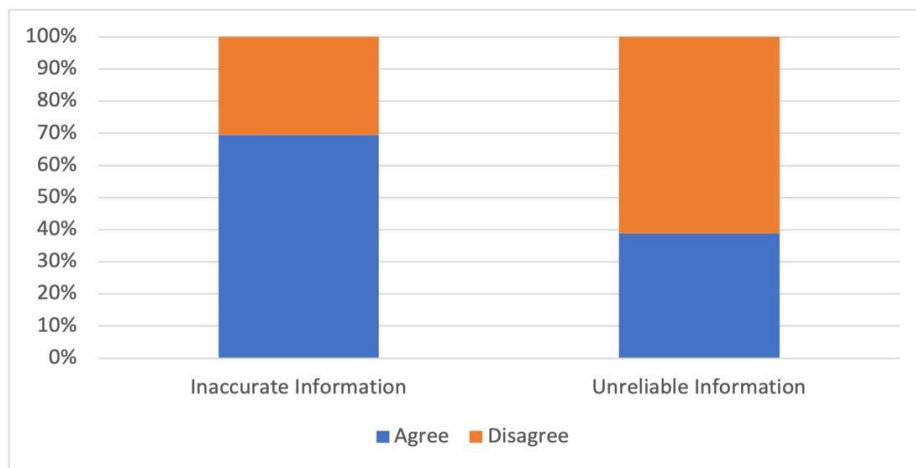


Figure 4. Inaccurate Information and Unreliable Information from Social Media

**Discussion**

Within the last ten years, the vast development of social media gave birth to various platforms, each with its own unique characteristic and appeal to society. Plastic surgeons are starting to utilize social media for branding purposes, patient acquisition, and public education.<sup>11</sup> This survey demonstrated WhatsApp as the most frequently used social media platform for patients, both in general social media engagement and in attaining information regarding cleft lip and/or palate. Our results are in line with a similar study done by Sorice et al.<sup>12</sup> While the survey is done in an aesthetic clinic, the study also surveyed patient’s preferred social media. On a daily basis, patients use mostly Facebook, followed by Instagram. Meanwhile, half of the patients opted for websites in aid to decide upon a physician or practice. In our study, WhatsApp had the most significant patient engagement and primarily utilized in obtaining information regarding cleft lip and/or palate. The participants in the survey are involved in an online community built in WhatsApp. However, for most, WhatsApp is a one-on-one platform; therefore it might require extensive effort to provide customized information to each patient inquiring about a particular issue. An alternative might be establishing an artificial intelligence-integrated chatbot with pre-answered questions to simplify the dissemination of information. Interactive content is more appealing than one-way communication. The use of WhatsApp as a tool to educate parents<sup>13</sup> and telemedicine consultations are significantly beneficial.<sup>14,15</sup>

Parents of CLP patients in big cities are more likely to look for information regarding their kids’ condition through the internet. They

usually query about the child’s diagnosis, look for psychosocial support from other parents, and find information about things to do before the operation.<sup>16</sup> Meanwhile, patients in our survey are more interested in things to do after operation. In a study looking at social media posts by parents of CLP patients in Facebook, queries were primarily seeking for information regarding CLP, such as regarding surgery, nutrition, hearing, orthodontia, speaking, sleeping, otitis media, suture, arm splints, surgical tape, surgery scar, and use of pacifier and nostril retainer.<sup>17</sup> Majority of information in social media are created from fellow parents, causing parents to question the reliability of the information, as demonstrated in our study.

Aside from providing general information regarding cleft or lip palate, social media also act as a tool to provide personalized patient information, such as visit schedules, test results, and individualized education. A platform can be designed and connected to social media for easy access. If possible, a multidisciplinary access may be opened for all attending physician, allowing for unrestricted access and comprehensive care. It is essential for the platform to meet all dimensions of health information technology model as described by Sittig et al.<sup>8</sup> These dimensions include hardware and software; clinical content, human-computer interface and people; workflow and communication; internal organizational policies, procedures and environment; external rules and regulations; and measurement and monitoring. Recommendations on development of such platform based on each dimension are presented in Table 2. Although it requires a lengthy course of action, a patient centered platform would benefit their experience.

**Table 2. Recommendations on Development of Preferred Social Media Platform for Cleft Lip and/or Palate Aligned with 8 Dimensions of The Sittig and Singh Sociotechnical Model**

Dimension	Recommendations
Hardware and software	Ensure availability on various type of devices, including personal computer, laptop, and mobile devices.
Clinical content	Provide educational video and articles about cleft lip and/or palate.
Human-computer interface	Incorporate not only educational contents but also diverse means of interaction, including discussion and one-on-one chat.
People	Involve patients, non-medical human resources (social workers, patient navigator, advocates, etc.), and clinicians (plastic surgeon, otorhinolaryngologist, physical medicine and rehabilitation specialists, orthodontists, etc.) in the development of the platform.
Workflow and communication	Collaborate with healthcare system to ensure accessible care for patients, this may include providing easy access to healthcare website or call center.
Internal organizational policies, procedures, environment	Develop local policies and strategies to evaluate platform users and usage
External rules and regulations	Create collaborative program with the government to warrant adequate dissemination of information regarding the platform to cleft lip and/or palate patients and integrate national clinical practice guideline (if available) and educational contents in the platform

One of the challenges in social media, is the education level and socioeconomic status of the patients. In developing countries, this might pose a significant concern as not every potential user can afford a device that can support various social media platforms. Indonesia, is unique in this manner. In 2020, the use of Internet reach up to 73.7% of the total population, with majority residing in the bigger cities.<sup>3</sup> This is beneficial for public health sectors if they are interested in using social media to educate people regarding health issues. However, false health-related information from social media is also a common oversight, causing misleading behavior by its readers. In India and Spain, social media use skyrocketed since they implemented a lockdown, at the same time, causing a surge in fake news shared within the application.<sup>19,20</sup> Hoaxes are easily spread through WhatsApp when it is forwarded to a group with many members. The information cannot be easily corrected as people cannot report the message as false.

Social media and information technology is an important tool in the healthcare industry. Nevertheless, the conventional method of patient education should be reinforced, considering possibilities of social media access difficulties and misuse. Nowadays, there are numerous mobile applications available that are directed towards healthcare. Through these online applications, patients may easily inquire information, consult a doctor, and even acquire medication. The presence of such applications has demonstrated a positive

impact towards the aid of other medical conditions, such as pregnancy care or depression.<sup>7,8</sup> An official platform to provide related medical education is helpful to make sure patients receive accurate information. By integrating the apps with social media, it would be possible to engage more users. Moreover, topics related to plastic surgery, including cleft lip and palate, can be incorporated into the application to educate patients further about this issue.

This study provides new insight into social media use amongst parents of CLP patients in a developing country. It can act as a baseline study for plastic surgeons to develop an additional educational tool for parents. However, this study also has its limitations. First, the questionnaire was not validated; secondly, the number of samples is not enough to represent the whole country, as the sample were collected from the same cleft support group, this has the potential to create bias; third, the study method does not present the impact of social media on CLP care and results. In the Indonesian population, high engagement in social media is observed regardless of their socioeconomic status. WhatsApp is the most popular, user-friendly, free-of-charge application that may aid medical education and information. Future study on the usability of a WhatsApp chatbot as a tool to provide patient education is needed to implement the idea of a comprehensive medical technology-based care and to explore how social media can impact CLP care through positive behavioural change

obtained from supplemental knowledge gained from the platform.

### Conclusion

Physician should consider the use of social media for patient education. A WhatsApp chatbot powered by artificial intelligence can be further developed and investigated for future use for this purpose.

### Disclosure

The authors have no commercial associations or financial disclosure that might pose or create a conflict of interest with information or materials presented in this article.

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