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Original Article

Contextualizing sociocultural beliefs about cleft, knowledge of the treatments, and factors associated with delay of treatment in Eastern Indonesia

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ABSTRACT

Introduction: Indonesia is a multicultural Asian country with a high incidence of cleft. This study contextualizes how patients' sociocultural backgrounds hinder cleft management in a diverse nation.
Material and methods: This study involved 202 families of cleft patients attending six tertiary care hospitals in South Sulawesi between 2021 and 2022. A mixed-methods, descriptive cross-sectional study employed semi-structured interviews and focus group discussions. Thematic content analysis was done using Murdock's causal attribution of illness. Knowledge of the treatments and surgery expectations used open coding. We held medical team focus group discussions to validate education on treatments. Cleft management education was thematically analyzed based on Indonesia's Minister of Health Decree.
Results: Two hundred-two families and ten medical teams participated. Thematic content analysis revealed common beliefs and factors that hinder medical treatments. The participants were 109 Buginese, 57 Makassarese, 16 Durinese, 8 Luwunese, 8 Torajanese, and 4 Mandarese. 22.3 % were unaware of causation, while 29.2 % attributed it to natural causes. About half of the interviewees believed in supernatural attribution. Even though 40 % of participants knew little about the surgery, they agreed that surgery improves appearance and speech. Medical treatments are delayed due to a lack of treatment knowledge, parents' concerns about surgical safety, and beliefs about causes.
Discussion: Indigenous societies in South Sulawesi believe in supernatural causes of cleft. Most had incomplete surgical treatment information. An intensive educational health program about causes, treatments, medical specialists, and treatment goals is warranted to enhance patient compliance with medical treatment, ultimately leading to improved health outcomes.

1. Introduction

Cleft lip and/or cleft palate (CL/P) is a common congenital orofacial deformity. The global incidence of CL/P was 0.45 per 1000 live births [1]. However, it has been observed that the incidence varies considerably according to ancestry, geography, and socioeconomic status, wherein the highest incidence was noted among Asian populations. A recent meta-analysis analyzing data from low- and middle-income countries found that the overall pooled incidence of CL/P was 0.75 for every 1000 births [2]. In Indonesia, one of the middle-income Asian countries, national basic health research was conducted in 2007, and the estimated prevalence was 0.12 % [3].

Indonesia is a multicultural country with a large population of 273 million persons, of whom 84.7% profess Islam [4]. Although Muslims dominate the country, it is inhabited by millions of people who adhere to Christianity, Hinduism, Buddhism, and Confucianism, making Indonesia a diverse land of religious beliefs and practices. More

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than 1.300 ethnic groups with their languages and customs populate the country [5].

There is no doubt that culture and religion are deeply involved in conceptualizing medical conditions and illness; in particular, they modulate people's beliefs about the etiology and choice of interventions. Macionis defined beliefs as specific thoughts or ideas that people hold to be true, and understanding people's beliefs on disease causation is imperative to predict their behaviors in seeking treatment [6]. When the medical teams do not take into account the patient's sociocultural beliefs, this may affect the patient's willingness to accept the medical advice provided [7]. Till now, Murdock's illness theoretical model has been widely used in anthropological studies that intend to understand general population beliefs about illness causality. This model classified beliefs into two broad constructs: (1) natural and (2) supernatural causes, with subcategories within each [7]. About CL/P, a wide range of beliefs was found concerning its etiology and that, in most countries, it belonged to supernatural causes [8,9].

A study from Africa, particularly Nigeria, showed that some ethnic groups attribute the etiology of CL/P to evil and ancestral spirits. In contrast, other groups thought God's will was the dominant cause. Likewise, Lee et al., found that a group of Chinese people believe that putting sharp objects on the bed when a woman is pregnant results in her baby being born with CL/P. Unfortunately, misconceptions on CL/P causation by cultural views have been reported to result in multiple devastating consequences, including leaving the patients untreated, stigmatization, and infanticides [10–13]. This emphasizes the importance of understanding CL/P causations within a cultural context.

Understanding the indigenous communities' perception of the CL/P causations and their knowledge about suitable biomedical treatments will help policymakers design effective healthcare strategies to serve these communities. In a diverse cultural region like South Sulawesi in Indonesia, the perception of the indigenous community on the causes and knowledge of treatment for CL/P have yet to be described. Henceforth, this study aimed to explore in depth the beliefs about the etiology of CL/P among parents and patients' caregivers based on their cultural and religious backgrounds, assess their knowledge about available medical treatments, and their expectations to take surgery. In addition, we conducted focus group discussions with the medical team involved in patient care to explore the content and format of the education that has been undertaken. Through this exploration, we aim to uncover any factors hindering the delivery of comprehensive care.

2. Material and methods

2.1. Material

Treating CL/P in multicultural societies with low socioeconomic conditions is particularly challenging. Logistical and financial problems are exacerbated by the extreme difficulty of recruiting patients, particularly in remote regions, far from referral hospitals [14]. Hasanuddin University Dental Hospital, the Government of South Sulawesi, and Celebes Cleft Center (CCC) conducted numerous free surgical missions in various regions of Eastern Indonesia between 2021 and 2022 in collaboration with several local hospitals [15]. A cross-sectional descriptive study was conducted on parents or family members who accompanied patients to CL/P surgery in six hospitals in five regions of South Sulawesi: Dr. Dody Sardjoto General Hospital-Maros, Hasanuddin University Dental Hospital-Makassar, Bhayangkara General Hospital-Makassar, Tenriawaru Public Hospital-Bone, Prof. A. Makkatutu General Hospital-Bantaeng, and Hj. Puang Sabbe General Hospital-Enrekang. Snowball sampling was used to recruit this study's population.

Before starting data collection, ethical clearance was obtained from the Hasanuddin University Health Research and Ethics Committee (Approval Number: UH14060319). All study subjects had provided written informed consent before participation. This involved giving the participants details about the study's rationale, the potential benefits and risks, and the procedures and informing them that the entire participation process is voluntary. There is no punishment for their drop-off.

The researchers conducted face-to-face and two in-depth interviews at various hospital locations and times. This serial interview helped verify and cross-check data. The participants were interviewed using a questionnaire from Naram et al. [16]. Since the questionnaire was in English, three professional translators used a forward-backward protocol to translate it into Indonesian. The parents of outpatient children in the pedodontics department at Hasanuddin University Dental Hospital participated in a pilot study to clarify the translated questionnaire. The question items' reliability was assessed using Cronbach's alpha of 0.890 (<0.05). The focus group discussion was conducted in Hasanuddin University Dental Hospital for three days at different times to ensure validation of the information obtained. The study report followed the Consolidated Criteria for Reporting Qualitative Research (COREC) [17]. The first author (HH), a Celebes Cleft Center social worker, and three female doctors (DA, CDS, and NE) who had worked as research assistants at Hasanuddin University's dentistry faculty for three years conducted the interview and focus group discussion. None of these interviewers directly treated CL/P patients. Under the supervision of the second (MR) and last authors(TF), the three research assistants transcribed, coded, and analyzed interview data.

3. Methods

This research applied a mixed-methods design using semi-structured interviews. Narrative data from interview transcripts were used to generate qualitative and descriptive-quantitative data. Thematic content analysis regarding the beliefs of the causes of CL/P was performed according to Murdock et al.'s causal attribution of illness (Table 1) [7]. Murdock et al. proposed the theory after studying 139 cultural regions in Africa, East Asia, and North and South America; therefore, it is regarded as the most comprehensive study to define beliefs on the causation of illness. Further, the knowledge of the treatments and expectations to take surgery, the open-coding method was used.

To verify the provided education on treatments, we conducted focus group discussions with ten medical teams involved in managing CL/P in the six hospitals during the surgical mission. We analyzed the content thematically, focusing on patient education, following the Decree of the Minister of Health of the Republic of Indonesia No. HK.01.07/MENKES/321/2019 [17]. The Decree mandates nine medical specialists for CL/P management from infancy to adulthood: Gynecologist, Plastic Surgeon or Oral and Maxillofacial Surgeon, Psychiatrist, Paediatrician, Clinical Nutritionist, Orthodontist or Prosthodontist, ENT Specialist, Physical Medicine and Medical Rehabilitation Specialist, and Periodontist. The Decree specifies procedural and objective requirements for each CL/P treatment type.

To evaluate the effectiveness of the educational model during the hospital stay, we implemented an instructional program within IDEAL Discharging Planning [18]. This model included determining the location and timing of educational sessions, utilizing effective educational models, scheduling follow-up treatments, selecting appropriate language, and providing guidance on conveying information in a suitable manner. After all, ATLAS.ti.8 was used to analyze qualitative data. IBM SPSS Statistics 28, however, was used to quantify, summarize, and analyze the quantitative data and describe the features of the narrative information.

Table 1
The causal attribution of illness (Murdock's Theories of Illness).

Causation	Definition
Natural causation	
1. Infection	Invasion of the body by a pathogenic microbe.
2. Stress	Exposure of the victim to physical or mental stress
3. Organic deterioration	The decline in physical capacity resulting from the age-related degeneration of a specific organ.
4. Accident	Suffering a physical injury that excludes both intentions of the victim and supernatural intervention.
5. Overt human aggression	The intentional infliction of bodily harm on another person.
Supernatural causation	
6. Fate	Individual astrological influences, fate, or the personification of ill fortune -luck
7. Ominous sensation	The experience of portent (not merely to portent illness)
8. Contagion	Exposure to a polluting object, substance, or individual
9. Mystical retribution	Act of violating a taboo or moral restraint: food, sensory, sex, etiquette, ritual, property, and verbal.
10. Soul loss	The temporary separation of the soul from the patient's body
11. Malevolent	The hostile, capricious, or punitive action of evil or offended supernatural beings.
12. Sorcery	Aggressive use of a magical technique by a human, either independently or with the aid of a sorcerer or shaman.

Table 2
Demographical information of the samples.

Variable Religion	Male, n (%)	Female, n (%)	Total, n (%)
Islam	56 (27.72)	137 (67.82)	193 (95.54)
Christian	5 (2.48)	3 (1.49)	8 (3.96)
Catholic	0 (0)	1 (0.5)	1 (0.5)
Total	61 (30.2)	141 (69.8)	202 (100)
X^2=4.521,df=2,p-value=0.104			
Occupation			
Housewife	2 (0.99)	123 (60.89)	125 (61.88)
Farmer	32 (15.84)	6 (2.97)	38 (18.81)
Merchant	15 (7.43)	2 (0.99)	17 (8.42)
School Teacher	1 (0.5)	4 (1.98)	5 (2.48)
Civil servant	1 (0.5)	4 (1.98)	5 (2.48)
Employer	2 (0.99)	0 (0)	2 (0.99)
Fisherman	2 (0.99)	0 (0)	2 (0.99)
Student	1 (0.5)	0 (0)	1 (0.5)
Other	5 (2.48)	2 (0.99)	7 (3.47)
Total	61 (30.2)	141 (69.8)	202 (100)
X^2=145.954,df=8,p-value=0.000			
Ethnic Group	Male, n (%) Male, n (%)	Female n (%) Female n (%)	Total, n (%) Total, n (%)
Buginese	26 (12.87)	83 (41.09)	109 (53.96)
Makassarese	19 (9.41)	38 (18.81)	57 (28.22)
Durinese	7 (3.47)	9 (4.46)	16 (7.92)
Luwunese	4 (1.98)	4 (1.98)	8 (3.96)
Torajanese	4 (1.98)	4 (1.98)	8 (3.96)
Mandarese	1 (0.5)	3 (1.49)	4 (1.98)
Total	61 (30.2)	141 (69.8)	202 (100)
X^2=6.769,df=5,p-value=0.238			
Educational background			
No school	3 (1.49)	5 (2.48)	8 (3.96)
Elementary School	16 (7.92)	49 (24.26)	65 (32.18)
Junior High School	11 (5.45)	28 (13.86)	39 (19.31)
Senior High School	20 (9.9)	47 (23.27)	67 (33.17)
Bachelor	11 (5.45)	12 (5.94)	23 (11.39)
Total	61 (30.2)	141 (69.8)	202 (100)
X^2=4.631,df=4,p-value=0.327			
Ethnic Group			
Buginese	26 (12.87)	83 (41.09)	109 (53.96)
Makassarese	19 (9.41)	38 (18.81)	57 (28.22)
Durinese	7 (3.47)	9 (4.46)	16 (7.92)
Luwunese	4 (1.98)	4 (1.98)	8 (3.96)
Torajanese	4 (1.98)	4 (1.98)	8 (3.96)
Mandarese	1 (0.5)	3 (1.49)	4 (1.98)
Total	61 (30.2)	141 (69.8)	202 (100)
X^2=6.769,df=5,p-value=0.238			

4. Results

4.1. Demographic characteristics

Table 2 shows the 202 participants' demographics. Most respondents (69.8 %) were women, and 61.8 % were housewives. The data shows that 44.5 % of participants attended secondary or high school. Half of the samples (53.9 %) were Buginese, 28.2 % were Makassarese, and the rest were Durinese, Luwunese, Torajanese, and Mandarese. The study included 95.5 % Muslims, 3.9 % Christians, and 0.5 % Catholics. The focus group team included a speech therapist, an orthodontist, two pedodontists, five oral and maxillofacial surgeons, and two prosthodontists (Table 6).

4.2. Beliefs about the causes

Beliefs prevailing in the study population concerned with the causes of CL/P vary greatly. Table 3 shows that the highest percentage of the respondents (55, 22.3 %) were uncertain or had no idea of the cause of a CL/P. Most respondents were Buginese (28, 11.4 %) and Makassarese (16, 6.5 %). Notably, we had 4 Mandarese respondents, and 3 had no idea about the cause of CL/P.

There were 30 (12.2 %) respondents attributed CL/P to genetic mutation. Twenty (8.13 %) of these respondents were Buginese, and six (2.44 %) were Makassarese. Some of them indicated the existence of another family member who also has a CL/P.

Thirty (12.2 %) participants attributed CL/P to medications taken by pregnant mothers without a prescription. This belief was also dominant between Buginese (15, 6.1 %) and Makassarese (14, 5.7 %).

Another 26 (10.57 %) respondents believed that God has a role over everything that occurs to a human, including CL/P. This belief was firm among Buginese (14 respondents, 5.6 %) and Luwunese (4 respondents, 1.6 %) but very low among Makassarese (3 respondents, 1.2 %). Other 18 (7.3 %) participants reported that CL/P was primarily attributed to the fathers' work as farmers. They assumed that the child's CL/P happened because of cutting trees during the antenatal period. Five female respondents (2.03 %) believed that CL/P was caused by their husbands who accidentally killed animals while working on the farm. Fishing was also thought of as a causation of CL/P by 16 (6.5 %) participants; 14 (4.5 %) were Buginese. Three informants (1.2 %) reported that their children had a CL/P for mocking a CL/P patient. So, they consider a CL/P either a reminder or punishment from God. Of note, one of the least common cultural beliefs regarding CL/P causation among our group of participants was cigarette smoking, wherein only one Buginese respondent (0.4 %) believed a mother's smoking caused cleft during pregnancy.

4.3. Participants' knowledge of the treatments

The participants' highest recorded response (78.7 %) was that the patients with CL/P needed surgical repairs (Table 4). The participants from *Torajanese*, *Luwunese*, and *Mandarese* ethnic groups reported

Table 3
Beliefs about the causes of CL/P.

Variable	Buginese n (%)	Durinese n (%)	Luwunese n (%)	Makassarese n (%)	Mandarese n (%)	Torajanese n (%)	Total n (%)
Belief of the cause of CL/P							
No Idea	28 (11.38)	3 (1.22)	2 (0.81)	16 (6.5)	3 (1.22)	3 (1.22)	55 (22.36)
Genetic	20 (8.13)	3 (1.22)	0 (0)	6 (2.44)	1 (0.41)	0 (0)	30 (12.2)
Medication	15 (6.1)	1 (0.41)	0 (0)	14 (5.69)	0 (0)	0 (0)	30 (12.2)
God's will	14 (5.69)	3 (1.22)	4 (1.63)	3 (1.22)	0 (0)	2 (0.81)	26 (10.57)
Cut tree	8 (3.25)	1 (0.41)	1 (0.41)	8 (3.25)	0 (0)	0 (0)	18 (7.32)
Fishing	11 (4.47)	0 (0)	0 (0)	5 (2.03)	0 (0)	0 (0)	16 (6.5)
Malnutrition	7 (2.85)	3 (1.22)	0 (0)	2 (0.81)	0 (0)	0 (0)	12 (4.88)
Fall	5 (2.03)	0 (0)	0 (0)	4 (1.63)	0 (0)	1 (0.41)	10 (4.07)
Cutting animal	6 (2.44)	1 (0.41)	0 (0)	1 (0.41)	0 (0)	1 (0.41)	9 (3.66)
Hooking	3 (1.22)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.81)	5 (2.03)
Stressful	3 (1.22)	2 (0.81)	0 (0)	0 (0)	0 (0)	0 (0)	5 (2.03)
Hunting	2 (0.81)	0 (0)	0 (0)	1 (0.41)	0 (0)	0 (0)	3 (1.22)
Mocking CLP child	1 (0.41)	0 (0)	0 (0)	2 (0.81)	0 (0)	0 (0)	3 (1.22)
Too tired	0 (0)	3 (1.22)	0 (0)	0 (0)	0 (0)	0 (0)	3 (1.22)
Born premature	2 (0.81)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.81)
Chemical essence	0 (0)	0 (0)	0 (0)	2 (0.81)	0 (0)	0 (0)	2 (0.81)
Cutting hair	1 (0.41)	0 (0)	1 (0.41)	0 (0)	0 (0)	0 (0)	2 (0.81)
Digging	0 (0)	0 (0)	0 (0)	2 (0.81)	0 (0)	0 (0)	2 (0.81)
Fasting	0 (0)	2 (0.81)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.81)
Old age pregnancy	1 (0.41)	1 (0.41)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.81)
Scissoring	1 (0.41)	0 (0)	0 (0)	1 (0.41)	0 (0)	0 (0)	2 (0.81)
Working hard	1 (0.41)	1 (0.41)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.81)
Bleeding in pregnancy	1 (0.41)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.41)
Drink vinegar	0 (0)	0 (0)	0 (0)	1 (0.41)	0 (0)	0 (0)	1 (0.41)
Environmental factor	0 (0)	0 (0)	0 (0)	1 (0.41)	0 (0)	0 (0)	1 (0.41)
Cigarette Smoke	1 (0.41)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.41)
Throwing comb	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.41)	1 (0.41)
Total	131 (53.25)	24 (9.76)	8 (3.25)	69 (28.05)	4 (1.63)	10 (4.07)	246 (100)

X^2=191.385,df=130,p-value=0.000(Some respondents supplied multiple reasons)

that the only treatment option they had knowledge about for CL/P was surgery. Of 112 (54.11 %) *Buginese* subjects, 84 (40.58 %) said they knew about the surgery but had no idea what type of surgery their children would receive. Similar knowledge was also noted among 44 (21.26 %) *Makasarese* respondents and 15 (7.25 %) *Durinese* respondents.

Five (2.24 %) of the study population had no idea about the available treatment for CL/P; three of them (1.5 %) were *Buginese,* and two (1.0 %) were *Makassarese*. The knowledge about gnatoplasty, orthodontic treatment, and plastic surgery was limited, each mentioned by one subject only.

4.4. Reason for taking surgery

CL/P patients need to be treated surgically at the right time to achieve acceptable appearance and function. We asked our informants about the influential factors for choosing surgery as a leading solution to treat their kids with CL/P. The majority, 69 (20.97 %) of the informants, shared that their main concern was improving the children's appearance (Table 5). However, Sixty-five (19.7 %) of the respondents hoped for speech intelligibility by having surgery, and the highest response for this reason was noticed among Buginese (37, 11.2 %). Concerning the Makassarese ethnic group, the most common reason for their agreement to do surgery for their children was solving the feeding problem (18 respondents, 5.5 %). There, 30 (9.1 %) respondents accepted surgical correction for their children to avoid bullying, and 20 (6.08) of them were Buginese. Other reasons for getting surgery were to increase self-confidence within the CL/P patients (21 respondents, 6.4 %), 14 (4.3 %) of them were Buginese, and 4 (1.2 %) were Durianes. Seven (2.1 %) Buginese and Makassarese participants reported that the main reason for accepting surgery for their kids was to enable them to attend school.

4.5. Patient education on management and factors associated with delay of treatment

Education about CL/P management has been provided during various stages: the first consultation, before surgical treatment, during

Table 4
Knowledge of CL/P treatments.

Variable	Buginese (n%)	Durinese (n%)	Luwunese (n%)	Makassarese (n%)	Mandarese (n%)	Torajanese (n%)	Total (n%)
Surgery	84 (40.58)	15 (7.25)	8 (3.86)	44 (21.26)	4 (1.93)	8 (3.86)	163 (78.74)
Three types of treatment	12 (5.8)	0 (0)	0 (0)	6 (2.9)	0 (0)	0 (0)	18 (8.7)
Two types of surgery	7 (3.38)	0 (0)	0 (0)	4 (1.93)	0 (0)	0 (0)	11 (5.31)
No Idea	3 (1.45)	0 (0)	0 (0)	2 (0.97)	0 (0)	0 (0)	5 (2.42)
A number of surgeries	2 (0.97)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	2 (0.97)
Lip surgery	1 (0.48)	0 (0)	0 (0)	1 (0.48)	0 (0)	0 (0)	2 (0.97)
Palate surgery	1 (0.48)	0 (0)	0 (0)	1 (0.48)	0 (0)	0 (0)	2 (0.97)
Gnatoplasty	1 (0.48)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.48)
Orthodontic treatment	0 (0)	0 (0)	0 (0)	1 (0.48)	0 (0)	0 (0)	1 (0.48)
Plastic surgery	0 (0)	1 (0.48)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.48)
Three types of surgery	1 (0.48)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.48)
Total	112 (54.11)	16 (7.73)	8 (3.86)	59 (28.5)	4 (1.93)	8 (3.86)	207 (100)

X^2=28.403,df=50,p-value=0.994 (Some respondents supplied multiple reasons)

Table 5
Reason for taking surgery.

Variable	Buginese n (%)	Durinese n (%)	Luwunese, n (%)	Makassarese N (%)	Mandarese n (%)	Torajanese n (%)	Total n (%)
Good Appearance	36 (10.94)	11 (3.34)	2 (0.61)	17 (5.17)	0 (0)	3 (0.91)	69 (20.97)
Normal speech	37 (11.25)	7 (2.13)	3 (0.91)	16 (4.86)	0 (0)	2 (0.61)	65 (19.76)
Solve Feeding problem	18 (5.47)	0 (0)	2 (0.61)	18 (5.47)	3 (0.91)	0 (0)	41 (12.46)
No Bullying	20 (6.08)	0 (0)	1 (0.3)	9 (2.74)	0 (0)	0 (0)	30 (9.12)
Better Confidence	14 (4.26)	4 (1.22)	0 (0)	3 (0.91)	0 (0)	0 (0)	21 (6.38)
Can go to school	4 (1.22)	0 (0)	0 (0)	3 (0.91)	0 (0)	0 (0)	7 (2.13)
Can smile	1 (0.3)	0 (0)	0 (0)	2 (0.61)	0 (0)	0 (0)	3 (0.91)
Can socialize with other	0 (0)	0 (0)	0 (0)	2 (0.61)	0 (0)	0 (0)	2 (0.61)
Her husband would come back after surgery	1 (0.3)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	1 (0.3)
Weight gain	0 (0)	0 (0)	0 (0)	1 (0.3)	0 (0)	0 (0)	1 (0.3)
Total	183 (55.62)	25 (7.6)	10 (3.04)	95 (28.88)	6 (1.82)	10 (3.04)	329 (100)
X^2=56.68,df=50,p-value=0.240 (Some respondents supplied multiple reasons)							

patient follow-up, during hospitalization, and before patient discharge. The types of follow-up treatment and scheduling for future treatments have always been communicated. However, on several occasions, patients and their families have had limited recollection of the treatment protocols discussed during education sessions. The medical team did not provide written instructions for follow-up treatments. Language barriers have also hindered communication between the medical team and the patients. Families with lower education levels and communication skills have also faced challenges in understanding and asking questions about the treatment information. Unfortunately, the information was not presented in an easily understandable manner, important details were not consistently reiterated throughout the patient's hospital stay. Due to the limited number of medical specialists, especially in various centers across the regions, communication time has been extremely limited. Patients must be referred to the city center in Makassar when further treatment is required. Another factor contributing to patients not returning for further treatment is a reminder system to notify parents when follow-up treatment is needed.

5. Discussion

Sociocultural beliefs influence people's perceptions of the causes of CL/P and how they make decisions about the treatment [17]. Gaining insight into cultural beliefs can facilitate clinician-patient collaboration and interactions in the development of treatments that are consistent with the patient's personal values. Our study contextualizes sociocultural beliefs about CL/P, elaborates on the knowledge of CL/P treatment, and reflects on the effect of these sociocultural factors on CL/P management. Our findings are especially useful both for international and local cleft missions undertaken in the Eastern part of Indonesia to equip the medical team with sociocultural knowledge to effectively cope with cultural differences.

Table 6
Characteristics of Informants Involved in focus group discussion (FGD).

Characteristics	Survey Respondents Count (%), Total *n* = 10	FGD Count, Total n = 2
Sex		
Male	5	2
Female	5	2
Age		
30–39	7	2
40–49	1	2
50–59	2	2
Institution		
Hasanuddin University Dental Hospital	6	
Dr. Wahidin Sudirohusodo Hospital	1	
Hasanuddin University Hospital	2	
Main Job Function		
Pedodontist	2	
Orthodontist	1	
Oral and Maxillofacial Surgeon	5	
Prosthodontist	1	
Speech Therapist	1	
Years of working experience in cleft care	Mean (range)	7.5 (0–14)

According to our study, 22.3 % of participants were unaware of the cause. Although most respondents (78.74 percent) indicated that it could be treated with a series of surgical procedures, they were uncertain about the procedures' types and stages. About half of the sample hoped their children would live a normal life following surgical treatment by improving their appearance and speech intelligibility. The patient education has included the Minister of Health's Decree on patient treatment protocols.

Despite being incompatible with biomedical perspectives, community-based religious and cultural beliefs regarding the etiology persist. Our research has revealed that the majority of our respondents believe in supernatural retribution. It was believed that CL/P was caused by taboo sensory acts, such as viewing a CL/P child during pregnancy or making fun of them. Other animal-related taboo behaviors believed to cause CL/P included hunting, fishing, cutting fish, cutting chicken, and killing a snake, shrimp, and squid. It was believed that borrowing and failing to return a chopper, using scissors, and digging with a knife by either the mother or father during pregnancy contributed to the birth of a child with CL/P. Additionally, some families believed that cutting bamboo, wood, or carving wood caused CL/P. Most of these mystical retributions have also been attributed to CL/P occurrences by the Malaysian population [18], indicating that our observation may be generalizable to societies with similar cultural backgrounds.

This study revealed no consensus among South Sulawesi families regarding the etiology despite the prevalence of CL/P. It is well-documented that religious communities frequently view congenital defects as God's will or fate. Approximately 85 % of our sample's Buginese, Makassarese, and Mandarese adhere to Islam, whereas the Durinese, Luwunese, and Torajanes commonly practice Islam and Christianity. Notably, 10 % of our respondents ascribed CL/P to God's will. This, in particular, was not surprising as 95 % of our sample were Muslims, and believing in the will of God is known to be a core feature of the Muslim religion. Likewise, a previous study in neighboring Malaysia found that the belief system for CL/P causation focused on God's will among a significant population (18 %). El-Shazly and coworkers explored the beliefs of Muslims and Hindus about the causation of CL/P in Gujarat, India, where the majority of the population adheres to religious beliefs [19]. In both religious communities, especially in rural areas, the cause of illness could hardly be separated from the idea that it was God's given. Similarly, two studies were conducted in Africa on other religious groups and reached the same

conclusion [20,21]. Of particular interest, such religious beliefs were shown to help families cope better and build psychological conditions that are more positive than negative [18,22].

This study validated the lack of knowledge about the causes of CL/P among the six major ethnic groups in South Sulawesi, wherein 22.3 % of the study population admitted their complete lack of knowledge of any attributed causes. Further, based on previous studies, using the medicine during early pregnancy without medical supervision was a risk factor in the birth of a baby with a CL/P, although it only has a limited role [23,24]. Indeed, 30 respondents indicated that mothers took medications without a prescription during pregnancy. Also, 46 parents were found to have consanguineous marriage, wherein Kanaan et al. noted that consanguineous marriage could contribute to having a child with CL/P [25,26]. Besides, 12 respondents believed the child had a cleft because the mother did not receive appropriate nutrition during pregnancy. This oversight is scientifically established to result in a deformity [27].

Generally speaking, several of our respondents' perceptions of illness causation were consistent with Helman's theory that advocated including the personalistic theory of diseases in modern medicine. In this theory, indeed, the societies linked illness to transgressions of a moral and spiritual nature, which we have found in the South Sulawesi population. Our sample linked the occurrence of CL/P to the disruption of living in harmony with other humans or wildlife. Additionally, in light of Murdock's theory of disease causation [7], it is apparent that out of six ethnic groups, four groups regarded etiquette taboo as being related to wrongdoing. These misdeeds were connected to parental behavior when the infant was still in the mother's womb. Nonetheless, it is worth mentioning that the patients' families should not be blamed for their beliefs, though their views might not be accepted medically. We believe that the parents, families, or patients attribute CL/P externally to destiny or superstition, for instance, as a coping strategy. Therefore, mutual understanding and building a trusting environment between patients and professionals would enable professionals to pave the way for patient's health beliefs and behavior changes.

Concerning knowledge about treatment, only five respondents acknowledged that they had no information about the kind of treatments that could be given to CL/P patients, whereas 78 % indicated surgery as the primary treatment. This result is encouraging, though the patient's family must be well-informed about surgical treatment steps and other therapies in detail during a surgical mission.

The worldwide recommended protocol for surgical treatment includes correct lip cleft between 10 and 12 weeks, while the primary palatoplasty is between 9 and 12 months [28]. In addition, education on the treatment management and protocol referring to the Decree of the Minister of Health of Indonesia has been conducted. However, the education mode needs to be improved. The education scheme recommended by the Agency for Healthcare Research and Quality, especially the IDEAL Discharge Planning, could be a recommendation [29]. The system provides a pattern of education that can be implemented while the patient is in the hospital by integrating care and visits, as well as being used as a point to provide education, especially education on follow-up care plans. With high-quality health services and awareness of CL/P patients' families in high-income countries, patients usually receive early evaluation and surgical repair, significantly improving their quality of life. However, the scenario is somewhat different in low and middle-income countries where poverty, lack of resources, and lack of awareness, among others, cause hurdles in operating a significant number of patients at the right time and proper age. Our study is an additional example, where some patients operated on when they were nine or ten years old. We observed a lack of awareness about the benefits of early intervention for CL/P. Nonetheless, in the end, the patient's families decided to take their children to undergo surgery after experiencing various social challenges, such as a lack of self-confidence, being bullied, having feeding and speech problems, and having poor overall aesthetic appearance. Even though most parents appeared worried about exposing their children to surgical corrections in their early childhood, their willingness for the possibility that the kids might have normal social and academic lives was overwhelming. Some parents and caregivers of cleft patients clearly expressed the hope that their children would be able to attend school, be educated, and obtain reputable employment.

Given the growing interest in international volunteer work, particularly in surgical missions for cleft lip and palate, it is crucial to provide culturally competent care. This requires foreign surgeons to gain a deep understanding and respect for the patients' cultural background, in order to foster an environment grounded in trust. This indeed is important as cultural beliefs can heavily influence the patient's perceptions of medical care, their willingness to seek help, and their adherence to treatment plans. Our study thus provides valuable insights into the cultural backgrounds of CL/P patients and their families in the Eastern part of Indonesia, facilitating the mission of international surgical teams.

The findings of this study should be understood in the context of some limitations. First, this study focused on beliefs and knowledge among parents and caregivers of CL/P patients. However, other groups such as physicians, nurses, cultural leaders, religious leaders, and shamans should be investigated to show a genuine perspective of the entire community and get a broad view of societal beliefs in South Sulawesi. Second, our study assessed only the beliefs and knowledge about CL/P, but other crucial aspects, like nuclear and extended families' reactions and the patient's behavioral patterns, were not explored. Another important flaw of our study was recruiting the subjects from a clinical setting, meaning no information about those who did not receive any treatments. Despite these limitations, our study provided unique insights into the perceptions among indigenous communities in South Sulawesi about CL/P, which might help policymakers design effective strategies focusing mainly on educating society about the etiology and the availability of CL/P treatments. In addition, our study contextualizes sociocultural beliefs about clefts, knowledge about treatment, and factors associated with treatment delays in a multicultural world.

In conclusion, the current study demonstrated that the multiethnic indigenous societies in South Sulawesi hold multiple sociocultural beliefs on CL/P simultaneously, wherein supernatural causes are predominant. Additionally, most participants' communities had incomplete information about surgical procedures, particularly no clear information about timing, types, and the number of surgeries the patients may receive. Establishing intensive and sustainable educational health programs to increase knowledge about the causes and treatment of the patients may be warranted. By being culturally aware, local and international healthcare providers can enhance patient compliance with medical treatment, ultimately leading to improved health outcomes.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Muhammad Ruslin: Writing – review & editing, Data curation, Conceptualization. **Aisha AH. Al-Jamaei:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Ellen M. Van Cann:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Marco N. Helder:** Writing – review & editing, Validation, Supervision, Methodology. **Andi Tajrin:** Writing – review & editing, Supervision, Investigation, Data curation. **Tymour**

Forouzanfar: Writing – review & editing, Validation, Supervision, Project administration, Methodology, Formal analysis, Data curation, Conceptualization.

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