

# Misinformation and Readability of Social Media Content on Pediatric Ankyloglossia and Other Oral Ties

Lindsay Booth, MD; Abdullah Aldaihani, MD; Jacob Davidson, MSc; Claire Wilson, PhD; Claire Lawlor, MD; Paul Hong, MD, MSc; M. Elise Graham, MD

 Supplemental content

**IMPORTANCE** Diagnosis of pediatric ankyloglossia and other oral ties is increasing in part due to social media, leading to more frenotomies and excess medicalization of often normal anatomy.

**OBJECTIVE** To assess the accuracy and readability of social media content on pediatric ankyloglossia and other oral ties.

**DESIGN, SETTING, AND PARTICIPANTS** In this cross-sectional study, the top 200 posts on an image-based social media platform tagged with *#tonguetie*, *#liptie*, or *#buccaltie* were collected using a de novo account on March 27, 2023. Post metadata and caption and content text were extracted.

**MAIN OUTCOMES AND MEASURES** Misinformation was judged by a 30-point scoring sheet based on clinical practice guidelines and expert consensus that was developed by 3 fellowship-trained pediatric otolaryngologist-head and neck surgeons. Readability was assessed using the Flesch-Kincaid Grade Level, Flesch Reading Ease, and Simple Measure of Gobbledygook scales. Quality was scored using the *JAMA* Benchmark Criteria.

**RESULTS** After removing duplicates and irrelevant content, 71 unique posts from 68 unique accounts were included in the analysis. Business and practice accounts made up most of the account types (60 [84.5%]) compared with individual and personal accounts (11 [15.5%]). Most accounts (49 [69.0%]) were run by individuals who self-identified as health care practitioners, and 21 posts (29.6%) originated from accounts of individuals who self-identified as International Board Certified Lactation Consultants (IBCLCs). On average, the content corresponded to a ninth-grade reading level per Flesch-Kincaid Grade Level. Quality of posts as rated by the *JAMA* Benchmark Criteria corresponded to a median score of 3.0 (IQR, 2.0-4.0). Of the 71 posts, only 8 (11.3%) contained no misinformation. There was a significant difference in misinformation prevalence between accounts run by IBCLCs vs non-IBCLCs, with posts from IBCLCs less likely to contain over 50% misinformation (odds ratio, 0.22; 95% CI, 0.06-0.81), compared with posts from non-IBCLCs.

**CONCLUSIONS AND RELEVANCE** This study found a high frequency of misinformation in social media content on ankyloglossia. Most content was generated by self-identified health care practitioners but not physicians. Furthermore, the grade level of the content reviewed was above that recommended for the public. As the public increasingly looks to social media for medical information, health care practitioners should correct medical misinformation.

**Author Affiliations:** Faculty of Medicine, University of British Columbia, Kelowna, British Columbia, Canada (Booth); Division of Otolaryngology–Head and Neck Surgery, Department of Surgery, Dalhousie University, Halifax, Nova Scotia, Canada (Aldaihani, Hong); Division of Paediatric Surgery, London Health Sciences Centre, London, Ontario, Canada (Davidson, Wilson); Department of Otolaryngology, Children's National Medical Center, Washington, DC (Lawlor); Department of Otolaryngology–Head and Neck Surgery, Schulich School of Medicine and Dentistry, Western University, London, Ontario, Canada (Graham).

**Corresponding Author:** M. Elise Graham, MD, Department of Otolaryngology–Head and Neck Surgery, Schulich School of Medicine and Dentistry, Western University, 800 Commissioners Rd E, PO Box 5010, London, ON N6A 5W9, Canada (elise.graham@lhsc.on.ca).

*JAMA Otolaryngol Head Neck Surg.* 2025;151(2):143-150. doi:10.1001/jamaoto.2024.4211  
Published online December 12, 2024.

Ankyloglossia is defined as a “condition of limited tongue mobility caused by a restrictive lingual frenulum.”<sup>1(p 600)</sup> A 25-year analysis of trends pertaining to the diagnosis and treatment of ankyloglossia in the US found that diagnosis of ankyloglossia and incidence of lingual frenotomy increased exponentially.<sup>2</sup> In comparison with the general population, children with ankyloglossia who had a frenotomy more commonly were male, had private insurance, and were in a midlevel to high median-income zip code.<sup>2</sup> These trends continued in an updated analysis from 2012 to 2016.<sup>3</sup> Other studies have found significant increases in the number of referrals for frenotomy and in the number of procedures being performed, reflecting the current clinical and cultural environment rather than true increases in incidence of ankyloglossia.<sup>4</sup> These trends are concerning given the contradictory evidence for frenotomy in many conditions.<sup>1,5</sup> A previous Cochrane review found that while frenotomy had a positive association with short-term nipple pain, evidence for an association with most conditions outside breastfeeding in other reviews was poor.<sup>5,6</sup> Even more controversial are other oral ties, including lip and buccal. To date, no associations between these entities and breastfeeding difficulties have been reported, and indications for surgical division are not supported in the literature.<sup>7</sup>

A previous study evaluated the quality and readability of ankyloglossia content on websites and found that while the quality, as assessed by the DISCERN instrument, was generally high, it exceeded the recommended reading level for the public.<sup>8</sup> Instagram (Meta) use has increased and has been found to be the second most searched platform for pediatric surgical conditions after X (formerly Twitter).<sup>9</sup> A previous analysis of X content pertaining to ankyloglossia was conducted to investigate the concerns and opinions of patients and health care practitioners.<sup>10</sup> The study did not formally assess misinformation prevalence or the accuracy of medical information provided but found that among posts by health care practitioners, 94.4% were pro-frenotomy.<sup>10</sup> From a demographic perspective, Instagram is one of the predominant platforms used by people of reproductive age.<sup>11</sup> As Instagram is increasingly used, this study sought to assess the quality, readability, and accuracy of Instagram content on ankyloglossia. We hypothesized that misinformation about pediatric ankyloglossia and other oral ties would be highly prevalent on the platform and that the information presented would be above the reading level for the public.

## Methods

### Search Strategy and Data Collection

This cross-sectional study looked at the quality of social media posts related to oral ties (ie, tongue, lip, and buccal). A de novo social media account was created to ensure a fresh algorithm when searching for posts. Searches were conducted on March 27, 2023, for the top 100 posts with #tonguetie and top 50 posts for each of #liptie and #buccaltie. As hashtags become more specific, fewer unrelated posts are identified; thus, a smaller number of posts with #liptie and #buccaltie were retrieved to achieve a more even distribution of relevant content across oral ties. In addition to social media

### Key Points

**Question** Is pediatric ankyloglossia and other oral tie content on an image-based social media platform accurate and at an appropriate reading level for the public?

**Findings** In this cross-sectional study of 71 unique social media posts pertaining to pediatric ankyloglossia and other oral ties, only 11.3% contained no misinformation. On average, the content corresponded to a ninth-grade reading level per Flesch-Kincaid Grade Level.

**Meaning** The findings suggest a high frequency of misinformation in social media content on pediatric ankyloglossia and other oral ties and that the reading level is above what is recommended for the public.

post data, account information was extracted for each unique account. Post metadata, including caption and content text, were extracted. Since this information is publicly available through social media, this study did not require ethics approval per the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.<sup>12</sup> The study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline.

### Accuracy, Quality, and Readability Scoring

Posts were excluded from analysis if they were not in English; did not pertain to tongue, lip, or buccal ties; or only concerned adults with ankyloglossia. Content was evaluated using several scoring systems. Posts mentioning treatment were evaluated using the DISCERN instrument, which is a validated 16-question instrument for evaluating the quality of health-related online information pertaining to treatment.<sup>13</sup> Quality was also scored using the JAMA Benchmark Criteria, which evaluates authorship, attribution, disclosure, and currency.<sup>14</sup> Readability was quantified for all included posts using Flesch Reading Ease, Flesch-Kincaid Grade Level, and the Simple Measure of Gobbledygook (SMOG) index.<sup>15</sup> Flesch Reading Ease is a formula that examines the total syllables, words, and sentences in text to provide an estimate of the ease with which the typical adult can read text.<sup>16</sup> It is scored from 0 to 100, with a higher score indicating that the text is easier to read.<sup>16</sup> The Flesch-Kincaid Grade Level also examines the total syllables, words, and sentences in text to provide an estimate of the grade level of particular text.<sup>16</sup> The SMOG index is a formula that uses the polysyllabic count of text to estimate how many years of education are required to understand the text.<sup>17</sup> It is frequently used to evaluate health care content, and lower numbers indicate fewer years of education required to understand the text.<sup>17</sup>

Accuracy of content was scored using a 30-point scoring sheet based on clinical practice guidelines and expert consensus. Three fellowship-trained pediatric otolaryngologist-head and neck surgeons (C.L., P.H., M.E.G.), including one with board certification in breastfeeding and lactation medicine (M.E.G.), designed and approved the scoring sheet through an iterative process. Categories included in the scoring were embryology, anatomy, epidemiology, symptoms, diagnosis, management, long-term sequelae, lip ties, and buccal ties (Table 1). Correct information and misinformation were marked, and a percentage-of-misinformation score across each category was

**Table 1. Misinformation Scoring Sheet With Representative Quotes**

Category, information scoring	Representative quote (profession)
<b>Embryology</b>	
The exact developmental etiology for ankyloglossia is unknown	<p>"I wish I had known what causes tongue and lip ties in babies—folic acid inhibiting your body's ability to absorb B vitamins. Yes, this recommended medication for pregnancy makes breastfeeding a nightmare!" (non-HCP)</p> <p>"Developing babies have a thin piece of tissue attaching the tongue to the lower jaw called the lingual frenum. This tissue usually detaches before birth, but in some cases, it is thicker than normal and the baby is born with an intact lingual frenum that makes it hard for the baby to stick out their tongue and move it side to side. This is a tongue tie, and it's important to treat it." (dentist)</p>
<b>Anatomy</b>	
The frenulum is a fold, not a discrete tubular structure	None
Innervation is predominately trigeminal (lingual), hypoglossal, facial, and glossopharyngeal nerves; the vagus nerve innervates the palatoglossus and provides taste on the epiglottis	"A part of the vagus nerve is found at the roof of the mouth behind the front teeth. Placing your tongue there stimulates the vagus nerve, calming tension. That's the correct position for our tongue. But if there is a tongue tie or someone is a mouth breather, their tongue cannot reach this spot. This can cause tension, anxiety, and chronic stress." (non-HCP)
Ankyloglossia is not a fascial band to toes and spine	<p>"One of the reasons I've become passionate about the proper diagnosis of oral restrictions and oral ties is because it affects more than just infant feeding. That fascia connects all the way down to your feet!" (doula)</p> <p>"The fascia in our abdomen is connected to the fascia in our mouth. This is why restrictive tissues have an impact on gut and nervous system function!" (nurse practitioner)</p>
<b>Epidemiology</b>	
Diagnosis of ankyloglossia is increasing	"In Brazil, all babies must be examined for tongue tie by law, similar to newborn screening laws for genetic diseases in the US. Perhaps this law is needed here. Some US hospitals and clinics have gag orders preventing anyone from mentioning tongue ties to parents, or they'll be fired. These rules are unacceptable and unethical. Tongue ties are real, and they can cause serious harm to people of all ages." (medical student)
Lip ties are not associated with tongue ties	"Lip ties can affect bottle and breastfeeding and they come hand-in-hand with tongue tie. Someone can have a tongue tie without lip tie, but they can't have a lip tie without also having a tongue tie." (certified holistic infant reflux specialist)
<b>Symptoms</b>	
Number 1 symptom is maternal pain with latch	"The latch might not be painful, but might be shallow or difficult, and this can be the first sign your baby is having trouble. This difficulty might be from oral restrictions, body tension, or body tightness. You should also look for reflux, excess spit-up, 'colic,' drooling, lip blisters, and snoring. If you are having trouble with latch, pain, or nipple damage, you should see a TOTs specialized lactation professional right away." (doula)
Other symptoms include poor weight gain and poor milk transfer	"Babies might experience difficulty with tongue movement, milk transfer, clicking sounds, inefficient or lengthy feeds, poor seal, poor weight gain, and poor suck" (IBCLC)
Tongue ties do not cause colic	"While bottle feeding, a tongue tie might cause clicking, milk leakage, slow/long feeds, sleeping during feeds, colic, hiccups, reflux, lips curling in, and nasal congestion.." (IBCLC)
Tongue ties do not cause reflux or aerophagia	"Tethered oral tissues can cause oral motor dysfunction. Suboptimal oral skills can lead to aerophagia, or swallowing of air. Swallowing air increases the volume of their stomach, which increases pressure and therefore spit-up. Other signs of tethered oral tissues include mouth breathing, snoring, gas, stressful feeds, torticollis, side or positional preference, bottle preference, leaking milk, clicking, poor weight gain, or feeding too slow or too quickly." (nurse)
Tongue ties do not cause mouth breathing	"Not treating tongue tie can lead to speech difficulty; chewing difficulty; pain and discomfort due to tension in head, neck, jaw, and shoulders; bruxism; mouth breathing; sleep difficulty; and sudden infant death syndrome (SIDS)." (dentist)
Tongue ties do not cause tension or torticollis	<p>"Babies greatly can benefit from soft-tissue release on the surrounding muscles. This helps release patters of tension, giving way better mobility and a better latch. It's possible that some babies need their lip and tongue tie revised if severe. However, even if revised, these babies desperately need soft tissue tension pattern evaluation to regain proper mobility and motion after their procedure." (chiropractor)</p> <p>"When your baby or child has a tongue tie or lip tie, it is like they are in the potato sack race feeding. Eating can be exhausting because muscles that normally may not be part of the process are called into action to 'compensate' so that they can still suck or chew and swallow. It is not just muscles in the face; this can include muscles in the head, neck, back, and shoulder region. It creates a lot of tension from overuse or misuse of how the muscles were designed to function, eventually leading to pain and other problems." (dentist)</p>
<b>Diagnosis</b>	
No gold standard diagnostic tool for tongue tie	None
Assessment while breastfeeding needed for diagnosis	"We meet the baby and parent as individuals as well as a dyad for feeding and day-to-day life. We do this most commonly in supporting families through tongue, lip, and cheek tie release procedures. We teach our parents to help babies optimize function before release so the baby can use their full range of motion after release." (IBCLC)
Ideally needs both an IBCLC and a physician for diagnosis	<p>"How do you know if your baby has a tongue-tie? Ask a midwife to take a look, or look yourself! For an official diagnosis you need to speak to someone who is specially trained." (midwife)</p> <p>"All babies should receive bodywork from a chiropractor, an osteopath, or a craniosacral specialist as part of standard care. The should also have multiple assessments for tongue, lip, and buccal ties with a functional dentist who specializes in tongue tie release." (nurse)</p> <p>"Oral restrictions are often missed due to lack of training of those caring for infants. Ties are diagnosed by specially trained chiropractors, myofunctional therapists, osteopaths, and dentists." (doula)</p> <p>"The parents are so happy with how baby is doing post tongue tie release. Look at the tension in the face before that is now all gone. Of course, the ENT said the baby didn't have any ties. They just don't know how to diagnose a submucosal tongue tie, don't examine for lip ties, and don't even know what buccal or cheek ties are." (physician)</p>

(continued)

Table 1. Misinformation Scoring Sheet With Representative Quotes (continued)

Category, information scoring	Representative quote (profession)
<b>Management</b>	
Must correct latch and position before offering tongue tie release	"We want to ensure the problem with breastfeeding is caused by the tongue tie, not anything else with the dyad, like low milk supply or difficulty latching baby." (IBCLC)
Must rule out other causes of breastfeeding pain (eg, vasospasm)	"If your baby has been referred for tongue tie release, consider a few things: Has a thorough breastfeeding examination been done? Did you have skilled help with latching and positioning? Have all other breastfeeding issues been excluded—for example recessed chin, low milk supply, tension, etc? Did you know that a recent UK study suggests there is no evidence 'to prove a causal relationship between posterior tongue tie and feeding difficulties in affected babies'? Also be aware that if someone has suggested that your baby should have lip or buccal tie release, did you know there is no evidence these entities cause breastfeeding difficulties?" (IBCLC)
Laser is not superior to cold instruments	"When bodywork is complete, we recommend one of our preferred providers is contacted for a cold laser release. These are highly trained individuals we collaborate with. The procedure is fast, there is little bleeding, and usually no pain by the next day." (IBCLC) "Treatment involves surgical release of tethered tissue with scissors or a laser. This is called a frenectomy and is performed by dentist, an ENT, or an oral surgeon." (dental hygienist)
Topical or injected anesthesia not recommended or needed in infants	"The procedure is fast but very difficult to watch. It probably took about 90 seconds. She got a numbing cream, was swaddled and strapped down." (non-HCP)
Sucrose should be provided for analgesia	None
Do not use wound massage or exercises	"Having the tongue tie snipped is never enough. It's only one piece of the puzzle. If you're still having issues postdivision, did you practitioner know about tension? Did you get myo-based functional exercises to do before and after? If not, maybe that's why you're still struggling." (non-HCP) "Make sure to organize a bodyworker (chiropractor, cranial osteopath, or physical therapist, etc) or perhaps a speech-language pathologist. Familiarize yourself with the oral stretches/exercises beforehand." (non-HCP)
Contraindications to frenectomy include bleeding disorders, micrognathia, Pierre Robin syndrome, and low tone or neurologic disorders	None
<b>Long-term sequelae</b>	
Ankyloglossia does not cause obstructive sleep apnea	"Outside of breastfeeding, oral ties can cause sleep apnea, bed wetting, speech delays, behavior issues/ADD/ADHD, poor oral health, body tightness, and tension." (doula) "In older children and adults, we can see symptoms of tongue tie, like sleep apnea, snoring, teeth gapping, anterior open bite, retruded mandible/chin 'overbite,' acid reflux, TMJ pain, mouth breathing, low tongue posture resulting in forward head posture to compensate, teeth movement/turning/crowding, premature tooth decay due to not being able to clean teeth, pain while brushing teeth, and so much more." (chiropractor)
Ankyloglossia does not influence facial, dental, or airway growth	"Babies do not 'outgrow' tongue ties, they develop compensations for them or they keep struggling through eating, speaking, etc, as they develop. When people say things like, 'they're just a fussy eater' or 'they'll grow out of the reflux,' we normalize the abnormal instead of holistically addressing the underlying cause." (IBCLC) "Tongue ties can be particularly harmful, as they can prevent full development of the airway. The tongue can't rest naturally against the roof of the mouth. We rely on this position without even knowing it, and in infants whose tongue cannot reach this position, they may develop strong dependence on coping mechanisms like pacifiers or thumb sucking. This prevents the full development of the airway and causes it to remain narrow." (dentist)
Unreleased tongue ties do not cause chronic pain (back, neck, or other)	"In a child, complications of tongue tie might include low weight gain, malnourishment, feeding or drinking difficulty, early breastfeeding cessation, body tension and misalignment, incorrect palate formation, crowded teeth, and speech impediments. Long term, complications of tongue tie include TMJ issues; headaches and migraines; neck, shoulder and back pain; facial tension and pain; grinding and clenching of teeth; difficulty chewing; sleep apnea; and incorrect tongue placement." (doula) "It's common to see changes to tongue posture, eating and breathing habits, sleep, dental development, and facial appearance when [tethered oral tissues] aren't treated. Long-term muscle compensations will often lead to chronic head, neck, and jaw pain." (dental hygienist) "There are many signs of untreated tongue tie in an adult, like frequent headaches, jaw pain and TMJ disorders, shoulder and neck pain, teeth grinding, sleep apnea and snoring, and digestive issues." (non-HCP)
<b>Lip ties</b>	
Lip frenula are normal structures	"A labial tie is a congenital abnormality of the labial frenulum preventing full range of motion of the lips, contributing to functional deficits." (occupational therapist)
Lip frenula do not need division for breastfeeding (do not cause breastfeeding problems)	"What are lip tie symptoms? Reflux from swallowing air, clicking sounds with breastfeeding, and tiring after feeds. What improvements do we expect with lip tie resolution? Longer nursing journey, decreased likelihood of tooth decay on front teeth, and improved speech in future." (dentist) "Let's get to the root of why my baby might not latch properly: lip/tongue tie, torticollis, proper positioning, discomfort, and/or mechanical issues." (chiropractor)
No standard lip tie diagnostic tool exists	None
Lip ties do not cause speech problems	"An issue like this can also cause dental issues and speech impediments later." (non-HCP)
No definitive relationship between lip frenula and dental carries but do use more care when brushing	"What I see every time a child has cavities is either poor nutrition from the mother and/or a lip or tongue tie." (chiropractor)

(continued)

Table 1. Misinformation Scoring Sheet With Representative Quotes (continued)

Category, information scoring	Representative quote (profession)
<b>Buccal ties</b>	
Do not divide buccal or cheek ties	<p>"Buccal ties are a congenital abnormality of the buccal frenulum restricting range of motion of the cheeks." (occupational therapist)</p> <p>"BUCCAL TIES MATTER. There may not be mountains of peer-reviewed journal articles proving their impact on oral function. But, years of clinical experience have shown me that buccal/cheek ties do make a difference in optimal oromotor function (despite what many providers say)." (IBCLC)</p> <p>"This is a tight frenum tissue attached between the cheek and the gum. Buccal ties are more rare than other oral ties and are often missed until much later on, although easier to spot. These can influence breast and bottle feeding. It can be difficult for babies to create a deep enough latch and adequate seals around the bottle teat. Buccal ties can create small pockets behind where food can get stuck and cause oral hygiene issues if not looked after properly." (infant reflux specialist)</p> <p>"There is currently no research or evidence to substantiate the removal of buccal ties in infants and children for feeding or growth and development purposes." (dental hygienist)</p>

Abbreviations: ADD, attention-deficit disorder; ADHD, attention-deficit/hyperactivity disorder; ENT, ear, nose, and throat; HCP, health care practitioner; IBCLC, International Board Certified Lactation Consultant; TMJ, temporomandibular joint; TOTs, tethered oral tissues.

calculated. Potential conflicts of interest were also recorded and described as a post derived from an account advertising a fee-based course or paid services for hire.

### Statistical Analysis

Descriptive statistics were performed to characterize the posts and social media accounts. The proportion of social media posts containing misinformation were analyzed using  $\chi^2$  tests. Odds ratios (ORs) and 95% CIs were calculated to quantify the magnitude of the association between variables. Continuous outcomes (ie, percentage of misinformation) were analyzed using the Kruskal-Wallis test for nonparametric data. The Kruskal-Wallis test was also used to generate effect size ( $\eta^2$ ), with 0.01 to less than 0.06 representing a small effect size, 0.06 to less than 0.14 indicating a moderate effect size, and greater than 0.14 indicating a large effect size. Pearson correlation coefficients were used to evaluate associations between continuous variables and represent effect size in these associations. All analyses were completed using SAS, version 9.4 (SAS Institute Inc). All posts were evaluated and scored by a single reviewer (L.B.). To establish inter-rater reliability of the misinformation scores, a second reviewer (A.A.) independently evaluated a random sample of half the posts ( $n = 35$ ) and an interclass correlation coefficient was calculated.

## Results

A total of 200 posts were identified with the tags *#tonguetie*, *#liptie*, and *#buccaltie*, and 189 remained after removing duplicates ( $n = 11$ ). The interclass correlation coefficient score for inter-rater reliability with the second reviewer's (A.A) scores was 0.873, which corresponded to good or excellent reliability.<sup>18,19</sup> As a result of the strong reliability in ratings, the scores from the main reviewer (L.B.) were used in the analysis.

Of the 189 unique posts, 118 did not contain any information relevant to pediatric oral ties and were excluded from the analysis. Of the remaining 71 posts, 22 (31.0%) were identified from the tag *#tonguetie*, 16 (22.5%) from *#liptie*, and 33 (46.5%) from *#buccaltie*. Most posts were single images (42 [59.2%]), with 7 (9.9%) being videos and 22 (31.0%) being multi-image carousels. The 71 posts originated from 68 unique

accounts with a median number of followers of 1902 (IQR, 456-7094). Most accounts (30 [66.7%]) originated in the US, with smaller proportions in Canada (7 [15.6%]), the UK (4 [6.7%]), Australia (3 [8.9%]), and Ireland (1 [2.2%]).

Business and practice accounts made up most of the account types (60 [84.5%]) compared with individual and personal accounts (11 [15.5%]). Most accounts (49 [69.0%]) were run by individuals who self-identified as health care practitioners, with the most common self-identified professions represented in the **Figure**. A minority of posts (21 [29.6%]) originated from accounts of individuals who self-identified as International Board Certified Lactation Consultants (IBCLCs). Of the 71 included posts, 29 (40.9%) were from an account with a potential conflict of interest, such as a paid course or the account owner's clinical services for hire. Several professions and designations that were referenced on accounts are described in the eTable in **Supplement 1**.

Of the 71 posts analyzed, most mentioned tongue ties (61 [85.9%]), with 35 (49.3%) mentioning lip ties, 21 (29.6%) mentioning buccal ties, and 6 (8.5%) mentioning posterior tongue ties. The post metadata, readability, and misinformation scoring is summarized in **Table 2**. Overall grade level determined by the Flesch-Kincaid Grade Level corresponded to a ninth-grade reading level. Quality of posts as rated by the *JAMA* Benchmark Criteria corresponded to a median score of 3.0 (IQR, 2.0-4.0). Only 14 posts (19.7%) pertained to treatment, and thus, the DISCERN score was not calculated for the remaining 57 posts (80.3%).

Sixty-three posts (88.7%) contained misinformation, with 59 posts (83.1%) having 50% or more misinformation of the total information provided. There was a significant, albeit small, effect size ( $\eta^2 = 0.02$ ; 95% CI, 73.6-89.3) when analyzing the difference in median percentage of misinformation for accounts run by IBCLCs (median, 83.3%; IQR, 40.0%-100%) and non-IBCLCs (median, 100%; IQR, 85.7%-100%). Posts from IBCLCs were less likely to contain misinformation (OR, 0.22; 95% CI, 0.06-0.81) compared with posts from non-IBCLCs, with 14 posts (66.7%) from IBCLCs containing 50% or more misinformation compared with 45 posts (90.0%) from non-IBCLCs containing 50% or more misinformation. There was no difference in the proportion of posts containing 50% or more misinformation between accounts run by health care practitioners

Figure. Included Posts by Profession

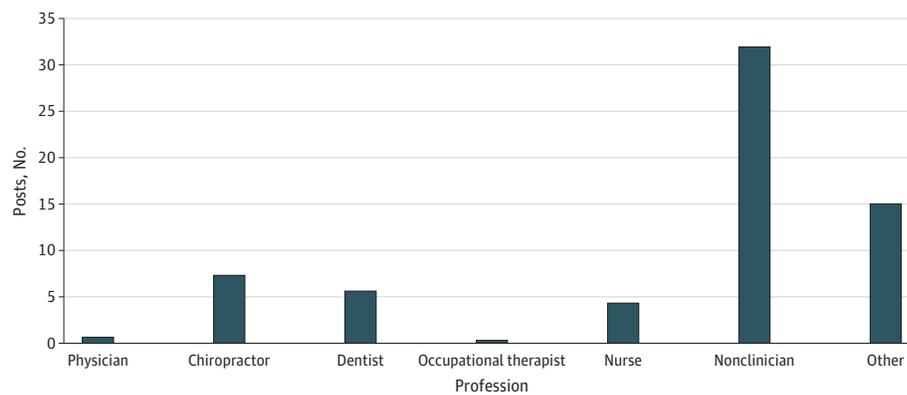


Table 2. Detailed Post and Account Information With Scoring for Relevant Posts

Variable	Median (IQR)			
	Overall (N = 71)	Tongue tie (n = 22)	Lip tie (n = 16)	Buccal or cheek tie (n = 33)
Likes, No.	54.0 (14.0-189.0)	99.5 (16.0-607.0)	45.5 (16.5-97.5)	49.0 (14.0-125.0)
Comments, No.	4.0 (1.0-27.0)	13.0 (0-43.0)	4.0 (1.5-21.5)	3.0 (1.0-24.0)
Hashtags, No.	17.0 (11.0-24.0)	19.5 (16.0-27.0)	13.0 (7.5-18.5)	16.5 (11.5-23.0)
Flesch Reading Ease score	61.6 (54.1-72.9)	65.8 (55.1-72.6)	66.0 (50.5-73.3)	59.2 (50.2-73.2)
Flesch-Kincaid Grade Level	9.0 (7.3-11.1)	8.8 (6.8-10.6)	8.1 (7.7-11.4)	9.2 (7.3-11.5)
Simple Measure of Gobbledygook score	8.0 (6.7-9.2)	8.0 (6.8-8.7)	7.5 (6.3-8.9)	8.7 (6.0-9.7)
JAMA Benchmark Criteria	3.0 (2.0-4.0)	3.0 (2.0-4.0)	3.0 (2.0-4.0)	4.0 (3.0-4.0)
Misinformation, %	100 (75.0-100)	100 (66.7-100)	100 (75.0-100)	100 (82.4-100)
Proportion of misinformation, No. (%)				
<50%	12 (16.9)	4 (18.2)	3 (18.8)	5 (15.2)
≥50%	59 (83.1)	18 (81.8)	13 (81.3)	28 (84.9)

or non-health care practitioners (OR, 0.39; 95% CI, 0.08-1.95) and business vs personal accounts (OR, 0.45; 95% CI, 0.05-3.85). The most common topics with misinformation were symptoms (38 [53.5%]), lip ties (26 [36.6%]), long-term sequelae (18 [25.4%]), and management (17 [23.9%]). Other common topics included buccal ties (11 [15.5%]), diagnosis (6 [8.5%]), anatomy (5 [7.0%]), and epidemiology (1 [1.4%]). Example quotes pertaining to each topic are collated in Table 1. There was a weak negative correlation between the total number of words in a post and the percentage of misinformation, such that as the number of words increased, the percentage of misinformation in a post decreased ( $r, -0.37$ ; 95% CI,  $-0.56$  to  $-0.15$ ). Posts that contained at least 1 piece of correct information originated from lactation consultants (8 posts [47.1%]), dentists (2 posts [11.8%]), nurses (2 posts [11.8%]), or other professions, such as dental hygienists, midwives, certified holistic infant reflux specialists, and speech language pathologists (5 posts [29.4%]).

Of the 71 posts, 8 (11.3%) contained no misinformation. The posts originated from the US ( $n = 4$ ), Australia ( $n = 1$ ), the UK ( $n = 1$ ), and Ireland ( $n = 1$ ). Most originated from business and practice accounts ( $n = 7$ ). A total of 6 posts (75.0%) originated from accounts run by individuals who self-identified as health care practitioners, with lactation consultant not otherwise

specified being the most common (3 [50.0%]). Three of the posts (37.5%) were from accounts run by individuals claiming the IBCLC designation.

## Discussion

To our knowledge, our study was the first to objectively assess the accuracy of pediatric ankyloglossia and other oral ties content on Instagram, which is the second most searched platform for pediatric surgery conditions.<sup>9</sup> Interestingly, most posts originated from *#buccaltie* ( $n = 33$ ) as opposed to *#tonguetie* ( $n = 22$ ) or *#liptie* ( $n = 13$ ), likely due in part to the specificity of the hashtag. Despite extracting more posts with *#tonguetie*, many of them were not actually related to oral ties, as it is common for people using hashtags on posts to get engagement even if the hashtags are unrelated or only distantly related to the tag itself. Only 8 of 71 posts (11.3%) contained no misinformation, and notably, no posts with no misinformation originated from physicians. Most posts (83.1%) had 50% or more of their total provided information identified as misinformation by our scoring sheet. As shown in Table 1, the misinformation provided ranged from incorrect to potentially harmful. Furthermore, the median reading level corresponded to

grade 9 on the Flesh-Kincade Grade Level, which is above the recommended grade-6 reading level for information to the public according to the American Medical Association.<sup>20</sup>

Misinformation about ankyloglossia and other oral ties is not benign. Infancy presents many challenges to parents and caregivers, and ankyloglossia and other oral ties was touted by many of the posts as being the root cause of any feeding dysfunction, reflux, or colic. Moreover, there was an implicit pressure to divide oral ties, as accounts forewarned of future complications that are not supported by evidence, such as sleep apnea, chronic pain, behavioral disorders, and dental carries. This push for ankyloglossia and other oral tie diagnoses may be at the expense of identifying the true etiology of the symptoms being experienced. Furthermore, having infants undergo frenotomies at the current rate represents a substantial amount of potentially unnecessary procedures and a large cost to parents. Tongue tie clinics have emerged, offering boutique frenotomy services with a CO<sub>2</sub> laser at steep costs. Many of the posts identified in our study were advertising their own courses and clinical services, representing a significant conflict of interest.

This study builds on previous work evaluating medical information on social media, which is increasingly a primary source of information for patients and parents. A study of social media use by parents of pediatric surgery patients indicated that 37.9% of parents used a social media platform to search for a surgical condition.<sup>9</sup> Social media content analysis has been performed for several conditions, ranging from carpal tunnel syndrome to wisdom teeth.<sup>21,22</sup> While social media use by physicians for science communication has increased, a substantial proportion of social media content pertaining to health information is created by nonphysicians.<sup>23-25</sup> Social media provides an opportunity for rapid dissemination of information; however, it is not without danger.

The prevalence of misinformation found in this study calls forth the question of who bears the responsibility of ensuring

online health information is accurate. Part of the CanMEDS competencies put forth by the Royal College of Physicians and Surgeons in Canada is to be a health advocate, including outside the clinical domain.<sup>26</sup> While there is an individual responsibility for those who choose to share health information to ensure the accuracy of their content, as shown in this study, misinformation continues to spread. There are currently minimal systems in place on social media platforms for fact or credential checking. Anyone can create an account, claim to be a physician or health practitioner, and provide medical information, whether it is accurate or not. As society moves increasingly into a digital age and parents increasingly look toward social media for health information for their children, it will be important to have accurate and accessible sources of information. Formal systems for verification of credentials for health care practitioners sharing health information and advertising health services as well as a transparent fact-checking processes are needed.

### Limitations

This study has limitations. The top posts for any given hashtag change frequently as new content becomes available, and thus, our sample captured the top posts during a single moment in time. Furthermore, we relied on self-reported data with respect to professions and qualifications as gathered from account metadata.

### Conclusions

The findings suggest a high frequency of misinformation in social media content on pediatric ankyloglossia and other oral ties. Most content was generated by self-identified health care practitioners but not physicians. This study highlights the current state of misinformation regarding oral ties on social media and serves as a call for expert-vetted health information to be easily accessible to patients and their families.

#### ARTICLE INFORMATION

**Accepted for Publication:** October 3, 2024.

**Published Online:** December 12, 2024.  
doi:10.1001/jamaoto.2024.4211

**Author Contributions:** Drs Booth and Graham had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

**Concept and design:** Booth, Aldaihani, Davidson, Lawlor, Hong, Graham.

**Acquisition, analysis, or interpretation of data:** All authors.

**Drafting of the manuscript:** Booth, Aldaihani, Davidson, Lawlor, Hong.

**Critical review of the manuscript for important intellectual content:** All authors.

**Statistical analysis:** Booth, Aldaihani, Davidson, Wilson.

**Administrative, technical, or material support:** Booth, Davidson, Wilson, Hong, Graham.

**Supervision:** Davidson, Lawlor, Hong, Graham.

**Conflict of Interest Disclosures:** None reported.

**Data Sharing Statement:** See Supplement 2.

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