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Assessment of Maternal Perceptions on Post-Surgical Follow-up in Managing Tethered Oral Tissues

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To the Graduate Council:

I am submitting herewith a thesis written by Taylor Winkel entitled "Assessment of Maternal Perceptions on Post-Surgical Follow-up in Managing Tethered Oral Tissues." I have examined the final electronic copy of this thesis for form and content and recommend that it be accepted in partial fulfillment of the requirements for the degree of Master of Science, with a major in Nutrition.

Katie Kavanagh, Major Professor

We have read this thesis and recommend its acceptance:

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(Original signatures are on file with official student records.)

Assessment of Maternal Perceptions on Infant Feeding, Post-Surgical
Management of Tethered Oral Tissues

A Thesis Presented for the
Master of Science
Degree
The University of Tennessee, Knoxville

Taylor Winkel
August 2021

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ABSTRACT

Background: Breastfeeding rates have increased over several decades. During that time period, diagnoses of infants' tethered oral tissue anomalies (i.e., "tongue-tie", "lip-tie") and clipping of these tissues, increased exponentially. Expert opinion is that increased breastfeeding rates explain much of this increase, though there is little research to support or refute the practice. Limited evidence indicates that, in part, increases appear to be driven by patient demand possibly resulting from exposure to the procedure via social media and informal peer-networks. To-date, there has been little direct exploration of maternal experiences with breastfeeding and diagnosis/treatment of infants with tethered oral tissue anomalies.

Objective: The objective was to explore, among mothers of infants ≤ 6 months, their experience breastfeeding an infant diagnosed with and receiving surgical intervention for at least one tethered oral tissue anomaly

Methods: This was a cross sectional, observational study, conducted online via survey. Recruitment occurred via social media posting, from August to September 2020. Mothers (≥ 18 years), currently or previously breastfeeding/chestfeeding an infant (≤ 6 months old), and with an infant diagnosed with and received treatment for ≥ 1 tethered oral tissue anomaly were eligible. The survey instrument consisted of demographic and breastfeeding/chestfeeding questions and questions about tethered oral tissue concerns/resolution

Results: Of 266 eligible screens, 49 responses were considered valid and complete. The sample was homogeneous in terms of maternal race (96% white), marital status (96% married), ethnicity (96% non-Hispanic/non-Latinx), and breastfeeding status (94% providing breastmilk, in some form, at time of survey). Forty-one mothers reported more than one tissue was released, most were confident in their ability to identify these tissues, and most felt involved in the decision to conduct the procedure. Lactation consultants were the most common source of information about tethered oral tissue anomalies (n=31) and referrals for treatment (n=18), and pediatric dentists were most likely to perform the intervention (n=28). Perceived breastfeeding pain improved in nearly all cases.

Conclusions: Results of this study indicate that lactation consultants are frequently serving as both information and referral sources for clipping of tethered oral tissues and mothers feel involved in the process and report pain resolution post-procedure.

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CHAPTER 1: LITERATURE REVIEW

Breastfeeding

Breast is Best

It is known that breastfeeding is almost always the best nutrition for an infant (Eidelman & Schanler, 2012; Lessen & Kavanagh, 2015). There are many potential benefits of breastfeeding for the mother and the infant, as well as benefits to public health. For example, compared to formula-fed infants, breastfed infants are more likely to experience greater immunity to infections, reduced risk of allergies, reduced risk of developing type 1 or type 2 diabetes mellitus, and potentially reduced risk of developing obesity (Eidelman & Schanler, 2012; Lessen & Kavanagh, 2015). For the mother, compared to women who formula feed, benefits include faster uterus recovery, decreased postpartum bleeding, potentially more rapid return to pre-pregnancy weight status, and protection from diseases such as breast and ovarian cancers and type 2 diabetes mellitus (Leung & Sauve, 2005; Lessen & Kavanagh, 2015).

Because of these benefits, The American Academy of Pediatrics (AAP) recommends that individuals breastfeed their infant exclusively until about 6 months of life, and then continue to breastfeed for at least up to a year of life along with complementary foods (Eidelman & Schanler, 2012). Based on these recommendations, *Healthy People* includes several objectives which can be used to assess specific breastfeeding behaviors as a nation and in subgroups (U.S. Department of Health and Human Services, 2019). Over the past 20 years, rates of most individual objectives have increased, and many have even exceeded the target rate (Table 1). In fact these data, reflecting 2017 births, indicate that duration of breastfeeding to 6 months of age, is the only objective that has not yet been met on the national level (Center for Disease Control and Prevention (CDC), 2020).

Table 1. Healthy People 2020 Breastfeeding Objectives and U.S. Breastfeeding Rates from the 2020 Breastfeeding Report Card (CDC, 2020)

Healthy People 2020 Breastfeeding Objective	Target Rate	U.S. Rate*
Increase the proportion of infants who are ever breastfed	81.9%	84.1%
Increase the proportion of infants who are breastfed at 6 months	60.6%	58.3%
Increase the proportion of infants who are breastfed at 1 year	34.1%	35.3%
Increase the proportion of infants who are breastfed exclusively through 3 months	46.2%	46.9%
Increase the proportion of infants who are breastfed exclusively through 6 months	25.5%	25.6%
Increase the proportion of employers that have worksite lactation support programs	38.0%	51.0%
Reduce the proportion of breastfed newborns who receive formula supplementation within the first 2 days of life.	14.2%	19.2%

*Reflects 2017 births.

Influences on Breastfeeding

Though nationally the United States is meeting most of the targeted rates for initiation, exclusivity, and duration (CDC, 2020), research indicates that up to 92% of those who initiate breastfeeding may experience problems which, in turn, increase the risk of early weaning (Colin & Scott, 2002; Chantry, 2011; Feenstra, Jørgine Kirkeby, Thygesen, Danbjørg, & Kronborg, 2018; Odom, Li, Scanlon, Perrine, & Grummer-Strawn, 2013). These breastfeeding problems differ somewhat based on infant age and/or maternal experience, but common themes include maternal pain during the feed, insufficient milk supply (real or perceived), and infant fussiness (Odom et al., 2013; Wagner, Chantry, Dewey, & Nommsen-Rivers, 2013). For example, in a longitudinal study, following 532 first-time mothers from pregnancy through 2 months postpartum (or until termination of breastfeeding, whichever occurred first), Wagner and colleagues reported the top concern on days 0 and 3 postpartum was having problems feeding the infant (44% and 54% of mothers, respectively) and on day 7 the top concern was painful breastfeeding (47% of mothers) (Wagner, Chantry, Dewey, & Nommsen-Rivers, 2013). The researchers reported that having infant feeding issues and concerns with milk supply within the first 14 days postpartum significantly increased risk of weaning by 2 months postpartum, regardless of maternal intent to breastfeed for a longer time period. Feenstra and colleagues (2018), in their study of 1437 mothers followed from pregnancy through 2 months postpartum, asked questions regarding early breastfeeding problems. From this sample, 576 mothers (40%) had reported they experienced early breastfeeding problems where 561 further described their issues. These experiences included difficult and/or painful latch, milk-supply concerns (not enough or too much), self-doubt, development of mastitis and other, unspecified, issues. Similarly, in their analysis of a subset of responses from the *Infant Feeding Practices Study II*

(IFPSII), Odom and colleagues (2013) explored reasons for not meeting breastfeeding goals (Odom, Li, Scanlon, Perrine, & Grummer-Strawn, 2013). Of the 1177 mothers who initiated breastfeeding, but had weaned by the time their infant was 2 months old, over half reported weaning earlier than originally desired (60%; n=706). These mothers were more likely to report concerns with lactation, including “latching-on” problems and painful, cracked and/or bleeding nipples, compared to those who had planned to wean before two months of age. The authors note that problems with latching-on may not only be painful, but are also likely to decrease efficiency of milk transfer, and ultimately reduce milk production (Odom et al., 2013). In fact, concerns about milk supply were more likely to be reported by the mothers who weaned before desired. Regardless, real or imagined, these concerns have a powerful effect on breastfeeding behaviors. Having an understanding of “normal” breastfeeding physiology may provide a window into what may be occurring when the breastfeeding situation is not optimal, beginning with an understanding of infant latch.

Infant latch

Efficient transfer of milk from the breast to the infant, achieved with limited discomfort to the mother, is critical to providing the infant with appropriate nutrition to support optimal growth and development (Caldwell & Turner-Maffei, 2016). This is achieved through establishment of proper “latching-on” to the breast by the infant. For the latch to provide efficient milk transfer, and be comfortable for the mother, the infant must open their mouth wide enough to be able to take in as much of the areolar tissue as possible. In addition, the infant should not latch on to the breast symmetrically. Rather, it should be an asymmetrical latch, with more of the areola visible above than below the latch. The wide mouth and asymmetric positioning allows the infant to latch much more deeply and allows the tongue to compress the

milk-production components of the breast (which are not located in the nipple), thus signaling the mothers' body to produce and expel the milk (Caldwell & Turner-Maffei, 2016). When in optimal latch position, the nipple should be only lightly compressed between the infant's tongue and soft palate. Rather, as a result of the negative pressure created by the suckling infant, the nipple should be able to freely stretch toward the back of the infant's mouth as well as expanding in width. In this way, proper latching-on greatly reduces risk of trauma to the nipple.

Painful nursing and infant latch

Conversely, when proper latch is not achieved and the infant instead "latches" onto the nipple, compression intended for the areolar tissue is exerted directly on the nipple and results in tissue trauma and significant pain to the mother (Caldwell & Turner-Maffei, 2016). Importantly, researchers have estimated that between 34% and 96% of breastfeeding women experience some amount of nipple trauma, and this trauma is a significant risk factor for early weaning (Bourdillon, McCauseland, and Jones, 2020; Dennis, Jackson, and Watson, 2014; Hornsby, Gurka, Conaway, and Kellams, 2019; Leurer & Misskey, 2015; Ricke, Baker, Madlon-Kay, & DeFor, 2005; Stuebe, Horton, Chetwynd, Watkins, Grewen, & Meltzer-Brody, 2014). In the study by Feenstra and Colleagues (2018), 40% of mothers indicated difficulty with establishing latch, followed by nipple trauma (38%). In another study looking at breastfeeding problems and early cessation, the majority of mothers also reported having breastfeeding difficulty in relation to getting the infant to effectively feed due to latch or effective suckling issues (Chantry, 2011). Similarly to the study by Feenstra et.al (2018), Chantry (2011) also found that mothers indicated the second most reported issue was breastfeeding pain. Reasons for poor latch might include problems with maternal positioning or with infant oral anatomy (Prasitwanaseree, Sinsuksai, Prasopkittikun, & Viwatwongkasent, 2019; Sroiwatana S, Puapornpong, 2018), a combination of

these, or some other issue entirely (Goyal, Banginwar, Ziyu, & Toweir, 2011). Though latch issues may be resolved by educating the mother about different breastfeeding positions and/or observing and correcting latch-on technique, a percentage of latching issues will continue to cause a barrier to successful breastfeeding (Dennis, Jackson, & Watson, 2014). In addition to contributing to pain, the lack of compression of the milk-production components of the breast seen with poor latch may result in reduced transfer of milk to the infant, increasing risk of reduced future milk production and the need for supplementary infant formula (Caldwell & Turner-Maffei, 2016); Ricke, Baker, Madlon-Kay, & DeFor, 2005) (Hornsby, Gurka, Conaway, and Kellams, 2019; Leurer & Misskey, 2015, Bourdillon, McCausland, & Jones, 2020; Dennis et al., 2014).

Perceived milk supply

Many mothers worry about not producing enough milk (USDA, n.d.), and while it is thought that only ~5% of women are not physiologically able to produce adequate amounts of milk for their offspring (Brownell, Howard, Lawrence, & Dozier 2012), painful nursing and perceived insufficient milk supply can ultimately lead to true milk supply issues, and to necessary supplementation and/or weaning if the situation is not resolved. In fact, concerns about low milk supply have been estimated to drive weaning about a third of the time, at least among women residing in higher-resource countries, though it can vary widely depending on the population (Galipeau, Baillot, Trottier, & Lemire, 2018; Gatti, 2008; Lou, Zeng, Huang, et al., 2014). For example, Feenstra et.al (2018), in a sample of 1437 mothers, those reporting having breastfeeding issues related to concerns of not having enough milk were more likely to have a problematic breastfeeding experience and a shorter breastfeeding duration. It is possible that a lack of understanding of the necessary frequency of feeds during the newborn period (e.g., ~8-12

feeds/24 hours), and that as the infant grows these feeds may become less frequent but will be greater in volume (USDA), may lead to doubt in one's milk supply. The lack of understanding of the dynamic behavior of breastmilk production, driven by the suckling infant, especially if it is perceived an infant is overly fussy or unsatisfied may contribute to the perception of low milk supply even if production is adequate (Caldwell & Turner-Maffei, 2016). Mothers who are not educated to use the number of wet and (primarily) soiled diapers, along with adequacy of infant weight gain, may be more likely to use subjective measures of infant disquiet to assess adequacy of milk supply (USDA, n.d.), thus increasing likelihood of early weaning. It is thought that concern with low milk supply is likely amplified by low maternal confidence in her ability to breastfeed (McCarter-Spaulding and Kearney, 2001). In fact, Feenstra and colleagues (2018) found mothers who had low self-efficacy regarding breastfeeding had the strongest association for early breastfeeding problems (aOR 2.67, CI: 1.99-3.59), meaning mothers within this study who were not confident in their ability to breastfeed or produce enough milk for their infant experienced more problems. Gatti (2008), who conducted a review of perceived milk supply found that 30% to 80% of mothers report perceived insufficient milk supply, and that the percentage of women who wean early due to perceived insufficient milk supply range from 23% to 56% of women, further demonstrating that perceived insufficient milk supply is an important reason for early weaning. Though this is a simplification of a complex situation, the cycle of painful and/or suboptimal latch, insufficient milk transfer, suboptimal signaling of the maternal milk-production and/or delivery mechanisms, and an unsatisfied and potentially inadequately nourished infant, can quickly become an overwhelming situation (Caldwell & Turner-Maffei, 2016). For the health of the infant, if not resolved, introduction of infant formula will become necessary. Unresolved latching issues may, in part, explain the increase observed in both

diagnosis and surgical interventions to correct tethered oral tissues among infants in the United States (Walsh, Links, Boss, and Tunkel, 2017; Wei, Tunkel, Boss, and Walsh, 2020). However, prior to discussing these increases, it is important to understand what a tethered oral tissue is and how it may interfere with proper latch.

Tethered Oral Tissues

There are two tethered oral tissues thought to be involved with latching onto the breast and the ability to create the suction needed to control the intake of a liquid feed (Messner, Walsh, Rosenfeld, Schwartz, Ishman, Baldassari, Brietzke, Darrow, Goldstein, Levi, Meyer, Parikh, Simons, Wohl, Lambie, Satterfield, 2020), though three are often discussed (Hentschel, 2018). The two of importance include the lingual and labial frenuli. It is issues with the degree of tethering of these frenum that are thought to sometimes impair proper latch (Messner et. al, 2020). The lingual frenulum refers to the fold of skin that runs along the base of the tongue and attaches the tongue to the floor of the mouth, while the labial frenulum attaches the upper lip to the gum line. Tongue-tie, or “ankyloglossia”, technically refers only to the length of the *lingual* frenulum, which is thought to be abnormally short or thick (Hentschel, 2018). In this situation, the infant has decreased ability to latch on or is “tongue-tied”. When an infant has tongue-tie, it may affect the infants’ ability to latch to the mother’s breast and may restrict the infant’s tongue movement (Ricke, Baker, Madlon-Kay, & DeFor, 2005). Similarly, the labial frenum (or “lip-tie”), may be involved in problematic latch, if abnormally short (Messner et al., 2020; Patel, Wu, Schwartz, & Rosenfeld, 2019). The third tissue, the buccal frenum, or “cheek-tie”, attaches the cheeks to the gums (Messner et al., 2020). Though the importance of the role these first two tethered oral tissues, especially if “tight” or “short”, in the ability to achieve an optimal infant latch (low or no maternal pain and adequate milk transfer) is not yet decided, it is thought that

the buccal frenum (aka, “cheek-tie”) is the least involved in the mechanism of controlling a liquid feed, and may be more important as rotary chewing ability develops later in the first year of life (Messner et.al, 2020). Despite being distinctly different tissues, issues with any of these are often included in the catch-all term ‘tongue-tie’. Though there may be many other reasons for painful latch (Khan & Ramirez, 2017), such as breast infection, Reynaud’s Disease, or poor positioning on the breast, it appears that release (e.g., clipping or lasering) of oral tethered tissues has become a prevalent practice in recent years, despite very little quality research supporting its role in reducing breastfeeding pain (Walsh & Tunkel, 2018; Wei et.al., 2020).

Recent evidence from the United States indicates that the diagnosis of ankyloglossia increased over 830% from 1997 to 2012 and frenulum-clipping procedures increased over 860% during that same period (Walsh, Links, Boss, and Tunkel, 2017). This increase has occurred in the absence of a solid body of research to support taking such an action (Walsh & Tunkel, 2018). In addition, infants may have more than one tissue clipped at once (Hentschel, 2018). Anecdotal evidence indicates that procedures to clip the labial frenulum (e.g., ‘lip-tie’) and/or the buccal frenum (e.g. ‘cheek ties’) are also occurring (Santa Maria, Aby, Truong, Thakur, Rea, & Messner, 2017; Messner, Walsh, Rosenfeld, Schwartz, Ishman, Baldassari, Brietzke, Darrow, Goldstein, Levi, Meyer, Parikh, Simons, Wohl, Lambie, Satterfield, 2020). For example, Caloway, Hersh, Baars, Sally, Diercks, & Hartnick, (2019) conducted an observational study of infants referred for specialized care, secondary to difficulty breastfeeding. Of 115 mother-infant dyads, 43 infants underwent some type of frenectomy surgery to release tethered tissues. In 10 cases only the labial tissue was released and in one case only the lingual tissue was released. However, both these tissues were released in the remaining 32 cases. However, another study conducted by LeTran et.al (2019) conducted a retrospective chart review in an outpatient

otolaryngology clinic, reviewing charts of infants seen during one year, and evaluated factors associated with surgical frenectomy. The authors found that otolaryngologists who did not perform a frenectomy were significantly more likely to have documented consultation with a lactation consultant, as compared to those performing frenectomy (55% vs 29%, respectively; $p=0.001$), meaning that surgical interventions may be reduced if families seek assistance from IBCLC's who may be able to correct the issue via non-surgical interventions.

The increase in diagnosis, identified by Walsh and Colleagues (2017), is of concern. There are variations in characteristics for those diagnosed with tongue-tie as well as for those who are referred for a frenectomy. For example, Walsh, Links, Boss, Tunkel, (2017) observed significantly higher rates of ankyloglossia diagnosis among children who were male (63.6%, 95% CI=58.6% to 68.5%, $p<0.0001$), had private insurance (60.1%, CI=54.8% to 65.5%, $p<0.0001$), had higher socioeconomic status (SES) (78.1%, CI=71.8% to 84.4%, $p<0.0001$), and were from the Midwest region (25.8%, CI=23.2% to 28.5%, $p<0.0001$), compared to the total discharge population during that time. LeTran et.al (2019) also found that male children were 2.5 times more likely to have a frenectomy compared to female children ($p=0.002$, 95% CI: 1.4 to 4.5), and were likely to be younger in age (2.6 months vs 3.5 months, $p=0.01$). Unger, Chetwynd, & Costello (2019), specifically conducted a prospective cross-sectional qualitative study using semi-structured interviews to further look into referral pathways. They interviewed a total of 9 healthcare professionals regarding their views on tongue-tie. Two individuals from each of the following disciplines were interviewed: International Board Certified Lactation Consultant (IBCLC), pediatric dentist, and pediatric chiropractor. Three speech language pathologists (SLP) were also interviewed. When asked about their education about how to assess or diagnose posterior tongue-tie, they all noted that they had not received formal training.

The most common education method mentioned was self-directed study, which may be an unreliable form of training (Unger, Chetwynd, & Costello, 2019). When each individual was asked about their scope of practice specific to this topic, chiropractors, IBCLC's, and SLP's each indicated this included assessment, but not diagnosis or treatment. The dentists indicated that both diagnosis and surgical treatment was in their scope of practice, but that they typically see infants as a result of any practitioner referral, and that they confirm the tethered oral tissue assessment (Unger, Chetwynd, & Costello, 2019). This finding was in alignment with a review that focused on describing the significance of ankyloglossia and the timing of treatment (Kupietzky & Botzer, 2005). These researchers found that otolaryngologists, dentists, and pediatricians indicated they are the ones who perform frenotomies. Though they also found that out of 425 pediatricians, 22% indicated they had performed a frenotomy. However, only 10% of these 22% said they had been taught the technique in residency (Kupietzky & Botzer, 2005). Two other studies conducted by, Muldoon, Gallagher, Mcguinness, & Smith (2017), and Walls, Pierce, Wang, Steehler, Steehler, & Harley (2014), found that the main specialist that identified and recommended the procedure was an IBCLC or hospital lactation consultant, which is contradictory to what was pointed out earlier by Letran et.al (2019) finding that those who saw an IBCLC had decreased the likelihood of surgical treatment.

Maternal Perceptions

Factors such as insurance status, SES, and region of residence in the U.S. indicate that something other than biology could be driving the observed changes (Walsh, Links, Boss, and Tunkel, 2017). Moreover, Power & Murphy (2014) found that 50% of infants with ankyloglossia who were breastfed were able to breastfeed without surgical intervention. Despite the established increase in frequency of tissue clipping, and the likelihood that more than just the lingual

frenulum is being clipped, there is no current clinical consensus regarding this procedure, with most clinicians falling into one of two sides of the issue. Either 1) wait for more research or 2) perform a minor procedure that carries very little risk. In the absence of any professional guidance, it appears that the increase in this diagnosis and performance of tissue clipping may be somewhat driven by the maternal consumer (Walsh, Links, Boss, and Tunkel, 2017), possibly secondary to the increased presence of the issue on social media and the internet in general (Messner, et.al, 2020); Aaronson, Castano, Simons, & Jabbour, 2018). However, at present, there is limited research describing the maternal experience with breastfeeding and tethered oral tissue interventions.

Seeking intervention

A few studies have explored reasons breastfeeding mothers may seek professional consultation for breastfeeding and issues with tethered oral tissues. For example, Muldoon, Gallagher, McGuinness, & Smith (2017), conducted a prospective cohort study with 289 breastfeeding women whose infant had been diagnosed with the need for and received a frenotomy. Eighty-nine of these women completed both pre- and post- questionnaires. Results of these questionnaires indicated the most common reason mothers sought a frenotomy was because of having difficulty latching infants to their breasts (n=37, 38%), though there was no objective measure of the tongue-tie impacting quality of latch. Another study by Wong, Patel, Cohen, & Levi, (2017) used an ethnographic content analysis to explore mothers' breastfeeding experience specific to having an infant with ankyloglossia. This was done by analyzing online discussions and these researchers found the most frequently discussed topic was difficulty latching (53/76 posts, or 69.7%), followed by a scissor frenotomy (48/76 posts, or 63.2%). Mothers mentioned cracked, bleeding, or painful nipples (60.5%, 46/76), though the researchers were unable to

determine if this was secondary to issues with tongue-tie. They also found that 63%, or 48/76 of threads asked about treatment options for ankyloglossia, showing that mothers use online discussions to support one another with difficulty breastfeeding from ankyloglossia, but also potentially could be influencing a mother to seek out options of treatment when they don't know if the procedure would even be necessary. Similar to the study by Wong and Colleagues (2017), Ray et.al. (2019), collected a total of 305 posts from online breastfeeding forums and found that concerns about breastfeeding difficulties were common (n=227, 74.43%). Nearly a quarter of mothers were worried about how the child behaved at the breast (i.e., was the child physically able to obtain enough milk during the breastfeeding session; n=77, 22%). Though less specific, ~6% (n=19) of mothers reported having a negative experience or experiences. relating to the mother having an awful experience (n=19, 6.23%). When these authors reviewed discussions of post-frenotomy outcomes and experiences, they found almost half of the posts declared mothers were satisfied with the outcome (n=133, 43.61%) meaning the procedure was worth it to improve breastfeeding, while a few said they were dissatisfied (n=31, 10.16%) meaning they were still having issues with infant latch and/or pumping. However, over one quarter of these mothers indicated having a more neutral attitude (n=86, 28.19%), discussing both the positive and negative aspects of having an infant who had received a frenotomy. Though not as common, 8.5% of mothers (n=29) expressed frustration, reporting conflicting diagnostic opinions between different health care providers, and between parents and these providers. Approximately 15% reported experiencing conflicting opinions regarding treatment (n=48). The authors concluded mothers found it difficult to make decisions, that there was limited discussion of associated risks from a surgical intervention, but that in general mothers reported having a positive experience. Findings from these studies indicate that mothers are generally satisfied with the outcomes of a

surgical intervention; however, there are limitations to the study designs. For example, review of online social media posts was limited to conversations mothers felt comfortable having in that environment, and it is likely that this does not provide a full picture of the experience.

Intervention impact

While one can increase their understanding of mothers' perceptions about tongue-tie via social forums, more objective measures, such as issue resolution may provide additional insight into the maternal experience. A critical measure used to assess effectiveness of intervention to resolve breastfeeding latch issues, is that of perceived maternal pain. A review identified 25 papers that looked at different scales used to assess maternal nipple pain and found that the numerical rating scale (NRS) and the visual analog scale (VAS) were the two most common tools used to evaluate this (Srinivasan, Dobrich, Mitnick, & Feldman, 2006). Srinivasan, Khoury, Puzhko, Dobrich, Stern, Mitnick, & Goldfarb (2018) selected the NRS when examining the influence of frenotomy on maternal nipple pain. The NRS measures maternal nipple pain in each breast, using a scale from 0 to 10, with "0" representing no pain and "10" representing the worst pain. At baseline, median pain score for the left nipple (n=26) was 3.0 (IQR = 5) and 3.25 (IQR= 5) for the right nipple (n=24). By day 14, post-frenotomy, pain scores in both nipples decreased significantly, by at least two points $p < 0.001$. Because it is so commonly used, and used especially in literature about breastfeeding and tongue-tie, collecting data using the NRS would allow for the greatest ability to compare outcomes

Schlatter, Schupp, Otten, Harnisch, Kunze, Stavropoulou, Hentschel (2019) designed a cohort study to determine breastfeeding problems in reference to tongue-tie and looked at improvements following frenectomy surgeries. In this study, 776 mothers of newborns were observed breastfeeding for lingual frenulum function and completed a breastfeeding

questionnaire that had standardized breastfeeding scores to determine their breastfeeding experiences. Of the 776 dyads in the study, 345 had breastfeeding issues, and 116 had tongue-tie; of those 116 with tongue tie 64 had breastfeeding problems, and only 30 underwent a frenectomy procedure. However, 45% of the breastfeeding cohort who had tongue-tie did not have breastfeeding problems at all and did not need to pursue surgical interventions. It is important to note that within the study a limitation arose due to some infants undergoing a surgical intervention without necessarily needing it because the parent actively opted for the procedure whether they did or did not have breastfeeding issues or other problems. By using the Assessment Tool For Lingual Frenulum Function (ATLFF) Schlatter et.al (2019), found that mother-infant dyads with tongue-tie that scored less than 11 points were predicted to have greater breastfeeding problems. Out of the 116 infants with tongue-tie, 33 infants had an indication for a procedure (score of less than 11), 23/33 had undergone a frenotomy and had significantly fewer breastfeeding problems at follow-up, where only 3/23 still had breastfeeding issues post procedure. While 6/10 infants who did not undergo a frenotomy still had breastfeeding problems. Schlatter et.al (2019) found there was a significant reduction of breastfeeding problems after frenotomy, according to Fisher's exact test ($p = 0.01$). From this they concluded from their study that newborn infants with lower ATLFF function scores that are experiencing breastfeeding problems do benefit from a frenotomy procedure. However, other research states that procedures may not be necessary to fix breastfeeding problems (Power & Murphy, 2015)

Because of research that shows that many infants with tongue-tie breastfeed successfully without medical intervention, there is a debate on what treatment is necessary. Ricke et.al. (2005) found that just because there was tongue-tie present in an infant's mouth, that didn't mean it was

always necessary to have a frenectomy. More so, that the function of the tongue was what was crucial for breastfeeding, not the appearance of the tongue. They found having tongue-tie increased the likelihood of exclusive bottle feeding at one week of life three-fold, as compared to similarly aged infants without tongue-tie. However, they also noted 80% of infants that had tongue tie successfully breastfed at one week. At one month of age, there were similarities between the tongue-tie and control infants who were being breastfed, so they concluded that only a minority of infants' breastfeeding experience was affected by tongue-tie. To further support this perspective, Wattis, Kam, and Douglas (2017), discussed that there were other professionals who believed breastfeeding problems could be fixed by enhancing knowledge on breastfeeding techniques, along with better understanding the diverse anatomies of infants' connective oral tissues. When parents were told their infant may need a frenectomy, this could be inappropriate advise. These parents then sometimes sought a second opinion from an IBCLC. Post examination from an IBCLC, parents were typically relieved to hear that surgery was unnecessary and that with proper breastfeeding support and advice, the issue could be resolved. This study provided further supporting evidence that a frenectomy may not be the best option for all infants with tongue-tie, and that it is important for parents to seek more education on this topic before scheduling the procedure.

Various studies have looked at methods and techniques of how to perform a frenotomy/frenectomy as well as what method may be more effective. What has not been looked at in depth is the complications that may arise postoperatively even with such a simple procedure. Varadan, Chopra, Sanghavi, Sivaraman, & Gupta (2019) collected data from various studies to identify postoperative and intraoperative complications associated specifically with a lingual frenectomy. One complication that was identified was reattachment issues which arose if

fibrous scar tissue developed due to the incomplete removal of the frenal attachment during surgery. The researchers reported that ~14% of adults and ~2% of children experienced reattachment (p. 550), and attributed this to incomplete removal of the fibrous tissue. Other complications included new or worsening speech disorders, excessive bleeding, formation of mucus cyst, numbness of tongue due to nerve damage causing temporary sensory loss, and/or infection (Varadan et.al, 2019). Due to the various complications that may occur, mothers should be knowledgeable and understand what could potentially happen if they pursue a procedure, however, the occurrence of these complication does not seem to be reported so further research could look into this to give mothers and healthcare workers a better understanding of this concept.

There are some studies that do show benefit in breastfeeding post frenotomy. Muldoon, et.al. (2017), found that out of 89 mother-infant dyads, 81 (91%) reported improvement in breastfeeding post frenotomy, while another 4 (5%) reported no improvement. Though specific to infants treated for a posterior tie, similar results were found by Srinivasan and colleagues (Srinivasan, Khoury, Puzhko, Dobrich, Stern, Mitnick, & Goldfarb, 2018). Hill and Pados (2020), recently released a systematic review that compared breastfeeding issues related to tongue-tie before and after procedures. They looked at 19 studies and found there was a decrease in maternal nipple pain immediately post intervention and up through 2-week post-intervention, when pain was re-assessed. Walsh and Benoit (2019), released an overview on ankyloglossia and the issues that arise, but they noticed that there were two systematic reviews regarding breastfeeding issues and non-breastfeeding issues and the impact of surgical treatment of ankyloglossia. Reports showed that breastfeeding and nipple pain reported by mothers improved,

however, the overall strength and quality of evidence in support of frenotomy is low (Walsh & Benoit, 2019).

Although there have been some studies reviewed here that sought to examine factors that may be associated with the increased rates of frenotomies, these studies examined data on how mothers felt via secondary data analysis on social media forum by analyzing social media posts, and there are few large cross-sectional studies that have been conducted to gather information from mothers directly. Specifically, there are limited studies that have surveyed mothers directly to explore how they learn about these procedures, what discipline(s) they perceive is/are providing referral for the procedures, and what discipline(s) they perceive is/are performing the procedures. For this reason, a study that collected data directly from the mother and asks about her perspectives regarding tongue-tie and breastfeeding was needed.

Research Aims

The research aims of this study were:

1. To identify where mothers receive information about the potential relationship between breastfeeding and tongue-tie.
2. To identify who is providing referrals for surgical intervention of tethered oral tissues
3. To identify what discipline(s) are performing surgical intervention of tethered oral tissues
4. To determine how confident mothers are in their ability to identify tethered oral tissue(s) was/were released.
5. To describe, retroactively, perceived maternal pain before and after the surgical release of the tethered oral tissue(s).

CHAPTER 2: MANUSCRIPT FOR PUBLICATION

Background

Breastfeeding is recommended as the best nutrition for an infant and that infants be exclusively breastfed for the first 6 months and then receive breastmilk and complementary foods until at least 12 months of age (Eidelman & Schanler, 2012; Lessen & Kavanagh, 2015). Breastfeeding has significant health benefits for infants and mothers, and benefits to overall public health (Eidelman & Schanler, 2012; Lessen & Kavanagh, 2015; Leung & Sauve, Kair, Flaherman, Newby, & Colaizy, 2015). Since promoting and supporting breastfeeding has been an area of focus for the federal government and relevant healthcare organizations (Eidelman & Schanler, 2012; USDHHS, 2011; USDA, 2016), rates of breastfeeding have consistently increased over the past several decades (CDC, 2020). In fact, the U.S. has achieved nearly all of the breastfeeding objectives outlined in the Healthy People document (CDC, 2020).

Somewhat in parallel with the increase in breastfeeding rates, the U.S. has experienced a tremendous increase the diagnosis of ankyloglossia (e.g., “tongue-tie”) (Walsh, Links, Boss, and Tunkel, 2017; Wei, Tunkel, Boss, and Walsh, 2020). For example from 1997 to 2012, diagnosis increased by 843% (Walsh et al, 2017), and increased by a further ~110% between 2012 and 2016 (Wei, Tunkel, Boss, and Walsh, 2020). Because neither infant oral anatomy nor birth rates have changed during this same time period, it has been suggested that this increase in diagnosis may be secondary to the increase in breastfeeding and the experience of latching an infant to the breast (Messner & Lalakea, 2000; Walsh et al, 2017). If latch is poor, it may not only result in a painful experience for the mother, but in insufficient milk transfer and an undernourished infant as well (Power, & Murphy, 2014). This is important because inadequate, insufficient, or painful latching is often provided as a reason for early weaning (Hornsby, Gurka, Conaway, and

Kellams, 2019; Leurer & Misskey, 2015). It has been suggested that in infant with tongue-tie may have reduced ability to latch to the mother's breast and may restrict the tongue movement necessary for effective suckling (Ricke, Baker, Madlon-Kay, & DeFor, 2005). There are three tethered oral tissues that may be involved in latching difficulties (Merritt, 2019), which include the lingual, labial, and buccal (or lateral) frenum (though the latter is somewhat more controversial) (Messner & Lalakea, 2000). Often, issues with any of these are included in the catch-all term 'tongue-tie'. Despite limited evidence supporting the association between breastfeeding and tongue-tie, it is commonly accepted as fact by the general public (Wei et al., 2020), and mothers seeking assistance with unresolved latching issues may partially explain the increase observed in diagnosis of issues with tethered oral tissues (Walsh, Links, Boss, and Tunkel, 2017).

While not particularly meaningful on its own, the increased diagnosis is of somewhat greater interest when considering one of its potential treatments, that of lingual frenotomy or "clipping" or "releasing" of the tongue-tie. The rates of lingual frenotomy increased by 866% between 1997 and 2012, and by an additional 52.8% between 2012 and 2016 (Walsh et al, 2017; Wei et al, 2020). It is thought that some of the increase in frenulum-clipping procedures in recent years is a result of practitioners trying to resolve the issue with pain and poor latch (Walsh, Links, Boss, and Tunkel, 2017). Interestingly, this increased medical intervention has occurred in the absence of a solid body of research supporting the practice (Walsh & Tunkel, 2018). Despite the established increase in frequency of tissue clipping, there is limited current clinical consensus regarding the effectiveness of this procedure (Messner, et.al, 2020). In the absence of professional guidance, research indicates that the increase in this diagnosis and performance of tissue clipping may be partially driven by the maternal consumer, in response to learning about

the procedure from lactation professionals (Messner & Lalakea, 2000) and from social media (Messner, Walsh, Rosenfeld, Schwartz, Ishman, Baldassari, Brietzke, Darrow, Goldstein, Levi, Meyer, Parikh, Simons, Wohl, Lambie, & Satterfield, 2020; Wei et al 2020; Walsh, Links, Boss, and Tunkel, 2017). The increase in consumer interest in this topic is further supported by the work of Aaronson and colleagues, who documented an ~25% increase in internet searches, from 2012 to 2017, using terms related to tongue tie (Aaronson, Castano, Simons, & Jabbour, 2018). Despite this demonstrated increase in consumer interest, and in diagnosis and surgical treatment, there has been limited direct exploration of this concept among mothers experiencing concerns with tethered oral tissue management(Illing, Minnee, Wheeler & Illing, 2019).

Given evidence of their potential role in the increase in diagnosis and surgical treatment of “tongue-tie”, and to support the call for shared decision-making between parent and practitioner regarding the release of these tethered oral tissues (Messner & Lalakea, 2000) it is critical to understand more about the maternal experience. Therefore, the aims for this project were to describe maternal perspectives on 1) where they got information about the relationship between breastfeeding and tethered oral tissue anomalies (e.g., “tongue-tie”); 2) which professions provided referrals for surgical intervention; 3) which profession(s) performed the surgical intervention(s); 4) their confidence in identifying which tissue or tissues were released; 5) their perceived level of involvement in decision-making and agreement with the procedure; and 6) their perceived pain before and after surgical release.

Methods

Research Design

A cross-sectional, observational study design was used to collect data via online survey. This study was approved by the University of Tennessee, Knoxville Institutional Review Board prior to implementation.

Survey Instrument

The survey gathered maternal demographic information, as well as how they learned about tongue-tie, who referred them for the procedure, who conducted the procedure, as well as pain experienced before and after the procedure. Mothers were also asked to identify which tissue or tissues was/were clipped and to assist with this, they were shown three drawings, each highlighting one of the three possible tissues. After responding to each image, mothers were asked to indicate how confident they were in their identification of the tissue (5 point scale, from “very confident” to “not confident at all”). Mothers were also asked how involved they were in the decision to release the tissue(s) (5 point scale, from “very involved” to “not involved at all”), how much they agreed or disagreed with the decision to have the procedure performed (5 point scale, from “strongly agree” to “strongly disagree”), and where the procedure took place. To assess nipple pain, mothers were asked to retroactively rate their pain, one-week prior to, one-week post-, and one-month post-procedure, using a 10-point visual analog scale, where “1” indicated no pain and “10” indicated the most pain. The full survey instrument can be found in the Appendix.

Study Population and Recruitment

The priority population recruited was women ≥ 18 years old, who had or were currently breastfeeding an infant ≤ 6 months of age, and whose infant had been identified as having issues with tethered oral tissues which were managed using a surgical approach. Recruitment occurred via social media posting from August to September 2020. Interested mothers completed an online screener. Those who were eligible to participate were provided with study information and, upon providing informed consent, were linked to the online survey.

Sample Size

A sample size of 100 was targeted for this exploratory study.

Data Collection

The survey was administered online through the Qualtrics platform. All questions were set as forced-response, and most included a 'choose not to respond' option. The response rate was evaluated on a regular basis, and recruitment efforts increased as needed. Data were downloaded at least weekly and stored on a secure server. Those who completed the survey were eligible to receive a \$10 electronic gift card. Upon completion of the survey, participants could select a link, where they could opt to leave their email address. Because emails could not be linked to survey responses, responses remained anonymous.

Data Analysis

Data were downloaded from the Qualtrics platform and analyzed using SPSS Statistics, version 26. Prior to analysis, the data were evaluated for incomplete or invalid responses. For example, if an infant birthdate indicated infant age >6 months. Incomplete (<80% complete) and invalid responses were removed from the dataset. Once a final dataset was established, descriptive statistics were used to characterize the study population. Maternal race, ethnicity, education, marital status, delivery method, income status (low vs. not low), breastfeeding behavior, identification of tissue(s) released, level of confidence in accurately identifying released tissues, as well as level of involvement in the decision-making process and agreement with the procedure were assessed as categorical variables, whereas maternal age, infant age, infant birth weight, and maternal nipple pain (pre-intervention and 1 week and 1 month post-intervention) were assessed as continuous variables. Other characteristics such as how mothers learned about procedures, who referred them to procedures, and who performed procedures were summarized and ranked from most-frequently selected to least-frequently selected, as mothers could select as many options from the presented lists as desired. Because the data are only descriptive, no statistical tests were conducted.

Results

Of the 479 screens completed, 49 of those were eligible, consented to participate, and completed the survey. Demographic characteristics of this sample are shown in Table 2. The sample was homogeneous in terms of maternal race (96% white), marital status (96% married), ethnicity (96% non-Hispanic/non-Latinx), and breastfeeding status (94% providing breastmilk, in some form, at time of survey) (data not shown). Maternal education varied greatly, with most women having a Bachelor's degree (n=27; 55%), closely followed by those with some college, but no degree (n=13; 27%). At the time of the survey, 89% of those providing breastmilk were doing so exclusively. Slightly less than half of the sample were categorized as low-income (41%), defined as having an annual income equal to or less than 185% of the federal poverty level, for household size, in 2019-2020. Mean maternal age was 29.6 (± 4.4) years, mean infant age, in months, was 3.3 (± 1.62) and the mean birth weight was 7.8 (± 1.0) lbs.

Table 3 describes the frequency of reasons mothers sought assistance from a healthcare provider, with the most frequently selected reason being difficulty latching (n=41), followed closely by the desire to improve feeding (n=33), and then excessive infant fussiness (n=19), and concerns the infant was gaining weight too slowly (n=14). Those who indicated seeking assistance to improve feeding, were subsequently asked to identify the type of food being offered at the time assistance was sought. Mothers could select "liquid", "solid", or "both liquid and solid". Of the 33 mothers selecting this reason, most reported offering liquid (n=30), two reported offering liquid and solid feeds, and one did not indicate feed type (data not shown). Painful latch (n=6) and cracked and/or bleeding nipples (n=3) were options added to the survey instrument, as in the first round of survey responses they were responses offered when selecting "Other" and asked to describe the reason.

Table 2. Demographic Characteristics of Mothers of Infants Diagnosed with Tethered Oral Tissue Anomalies, Resolved via Surgical Intervention (n=49)

Characteristics		N (%)
Maternal education	High school graduate or equivalent (GED)	4 (8)
	Some college, no degree	13 (27)
	Associates degree	5 (10)
	Bachelor’s degree or higher	27 (55)
Delivery method	Natural, vaginal delivery	11 (16)
	Medically managed, vaginal delivery	30 (43)
	Medically managed, cesarean delivery	8 (11)
Breastfeeding behavior, among those breastfeeding at survey completion (n=46)	Exclusively providing breastmilk, breastfeeding and/or providing expressed breastmilk (breastfeeding-only, n=20)	41 (89)
	Breastfeeding/expressing breastmilk + other foods/fluids	5 (11)
Low income ^a	Yes	20 (41)
	No	29 (59)
	Mean (SD)	
Infant birthweight (in lbs)		7.8 (1.0)
Maternal age (in years)		29.6 (4.4)
Infant age at survey completion (in months)		3.3 (1.62)

^aCategorized as “low-income” if income-eligible for the Special Supplemental Nutrition Program for Women, Infants, and Children (e.g., WIC), based on 2019-2020 guidelines

Table 3. Mothers' Reported Reasons for Seeking Assistance from a Healthcare Provider

(n=49)

Reason for Seeking Assistance*	Frequency Selected (ranked most to least)
Difficulty latching	41
Wanted to improve feeding	33
Infant with excessive fussiness	19
Infant gaining weight too slowly	14
Infant with excessive crying	8
Painful latch ^a	6
Wanted to improve speech	4
Cracked and/or bleeding nipples ^a	3
Other, unspecified	2
Infant gaining weight too quickly	1
Infant with gas ^a	1

*Mothers were asked to select all that apply.

^aAdded after the first 15 surveys were completed, as these were responses to the "Other" category.

Mothers were asked to identify which tissue or tissues was/were clipped (Table 4). For the lingual frenum, the classical tissue described by “tongue-tie”, 43 mothers (88%) indicated this tissue was released. However, only 5 of these 43 indicated this was the only tissue clipped (data not shown). The same number of mothers (n=43) noted the “lip-tie” tissue was released, with only 4 of these 43 mothers indicating it was the only tissue released. Finally, 7 mothers (14%) indicated their child had the buccal frenum (aka, “cheek-tie”) released, with all 7 reporting at least one other tissue was released. Forty-one mothers reported more than one tissue was released, with five reporting this included all three tissues. Of those reporting only two tissues were released, 33 reported only the tongue- and lip-ties were released and 2 reported only the lip- and cheek-ties were released. No mother reported only the tongue- and cheek-ties were released. Mothers were also asked to indicate their level of confidence in identifying which tissue was or was not released. Nearly all mothers indicated being *very confident* in identifying whether or not the lingual frenum had been clipped (96%; n=47; data not shown). Mothers were somewhat less confident in their ability to correctly identify the lip- and cheek-ties. Slightly more than 90% (92%; n=45) reported being *very confident* in their ability to correctly identify whether or not the lip-tie had been released, and 6% (n=3) were *confident*. Slightly more than three-quarters of mothers reported being *very confident* in identifying whether or not the cheek-tie had been released (76%; n=37), 8% (n=4) reported being *confident*, and 10% (n=5) responded as being *neutral*. Two mothers were *not confident* and one reported being *not confident at all*. Nearly every mother responded that she felt *very involved* in the decision to have the procedure conducted (n=48; data not shown). The remaining mother responded she felt *somewhat involved*.

Table 4. Maternal Identification of Specific Tethered Oral Tissue(s) Released (n=49)

Tethered Oral Tissue	Number Identifying Tissue as having been Released*
	n (%)
Lingual Frenum (e.g., classical “tongue-tie”)	43 (88)
Labial Frenum (e.g., “lip-tie”)	43 (88)
Buccal Frenum (e.g., “cheek-tie”)	7 (14) ^a

*Mothers could identify more than one tissue as having been released.

^aTwo mothers (4%) responded they were unsure if this tissue had been released.

The degree of agreement with the decision was high, with 46 mothers reporting they *strongly agreed* with the decision (data not shown). Three mothers reported the procedure occurred in the hospital setting, with the remainder reporting it occurred in a medical professional's office.

Responses to sources of learning about tissue revision are shown in Table 5, and are ranked in order of frequency of selection (most to least frequent). Mothers could select any number of the presented options. *Lactation Consultant* was the most frequently selected source of information (n=31), with *friends* (n=14), *social media* (n=13), *pediatric dentist* (n=12), and *pediatrician* (n=10) being the next most frequently selected sources. Those selecting *Lactation consultant* (n=31) were subsequently asked to identify specific credentials of the provider, if known. *International Board Certified Lactation Consultant (IBCLC)* was selected 24 times; *Certified Lactation Consultant (CLC)*, 2 times; *WIC peer counselor*, 1 time; and four mothers were unable to identify the credential. Most mothers (n=22; 45%) selected only 1 source from which they received information, while ~ 20% (n=10) selected 2 information sources.

Sources of referral are shown in Table 6. *Lactation consultant* was selected most frequently (n=18) as a source of referral, followed by *self-referral* (n=16), and *pediatrician* (n=15). Those selecting *Lactation consultant* were again asked to identify specific credentials of the provider, if known. *IBCLC* was selected 13 times; *CLC*, 2 times; *Community support individual*, 1 time; and 2 mothers were unable to identify the credential. Nearly 75% of mothers reported receiving a referral for possible surgical intervention from only one provider, whereas just over one-fourth reported receiving such referral from two different providers.

Table 5. Mothers' Reported Source(s) for Learning About Tissue Revision (n=49)

Information Source*	Frequency Selected (ranked most to least)
Lactation Consultant (LC) ^a	31
Friend	14
Social media	13
Pediatric dentist	12
Pediatrician	10
Midwife	5
ENT or Otolaryngologist	4
Nurse	4
Family member	3
General practitioner/Primary care provider (GP/PCP)	3
Occupational Therapist (OT)	3
Self-research	3
Pediatric chiropractor	2
Speech-Language Pathologist (SLP)	2
Doula	1

*Mothers were asked to select all that apply.

^aThose selecting "Lactation Consultant" (n=31) were subsequently asked to identify specific credentials of the provider, if known. International Board Certified Lactation Consultant (IBCLC) was selected 24 times; Certified Lactation Consultant (CLC), 2 times; WIC peer counselor, 1 time; and four mothers were unable to identify the credential.

Table 6. Mothers' Reported Source(s) of Referral for Tissue Revision Intervention (n=49)

Referral Source*	Frequency Selected (ranked most to least)
Lactation Consultant (LC) ^a	18
Self-referred	16
Pediatrician	15
Midwife	3
Pediatric dentist	3
Doula	2
ENT or Otolaryngologist	2
General practitioner/Primary care provider (GP/PCP)	2
Occupational Therapist (OT)	1
Pediatric chiropractor	1
Speech-Language Pathologist (SLP)	1
Did not need a referral	1

*Mothers could select all that apply for each of the categories

^aThose selecting "Lactation Consultant" (n=18) were subsequently asked to identify specific credentials of the provider, if known. International Board Certified Lactation Consultant (IBCLC) was selected 13 times; Certified Lactation Consultant (CLC), 2 times; Community support individual, 1 time; and 2 mothers were unable to identify the credential.

When mothers were asked to identify the discipline performing the surgical intervention (Table 7), the most frequently reported discipline was *pediatric dentist* (n=28), followed by *otolaryngologists* (n=9), and then *oral and maxillofacial surgeon* and *lactation consultant* (both selected 4 times). Three of the four lactation consultants reported to have performed the intervention were identified as *IBCLCs* by the mothers and one mother was unsure of the credential. Three mothers reported the intervention was conducted by two provider types, but it is unknown if this was because both disciplines were present or if there was more than one occurrence.

Perceived nipple pain, one week prior to, and one week and one-month post-intervention are shown in Table 8. All mothers provided a response to the question about pain prior to the intervention, but those who indicated their infant never latched on to the breast in question, post-release, were not asked to respond to post-release pain questions for said breast. Therefore, samples sizes vary slightly for these variables. Mothers reported, in general, greater pain in the right than the left nipple in the week prior to the intervention (5.2 ± 3.62 and 5.6 ± 3.67 , left and right, respectively). At one week post-intervention, improvement in pain was reported (n=47; 2.9 ± 2.53 and n=45; 3.0 ± 2.4 , left and right, respectively). By one-month post-intervention, pain levels appeared to continue to improve (n=44; 1.5 ± 1.65 and n=43; 1.6 ± 1.47 , left and right, respectively).

Table 7. Mothers' Reported Discipline(s) Performing Tissue Revision(s) (n=49)

Discipline*	Frequency Selected (ranked most to least)
Pediatric dentist	28
ENT or Otolaryngologist	9
Lactation Consultant (LC) ^a	4
Oral and maxillofacial surgeon	4
Pediatrician	3
General practitioner/Primary care provider (GP/PCP)	1
Nurse	1
Periodontist	1

*Mothers could select all that apply for each of the categories

^aThose selecting "Lactation Consultant" (n=4) were subsequently asked to identify specific credentials of the provider, if known. International Board Certified Lactation Consultant (IBCLC) was selected 3 times and one mother was unable to identify the credential.

Table 8. Perceived Maternal Nipple Pain Before and After Tissue Release (n=49)*

Time Period	Nipple in question	Mean Pain Score (SD)	Range
One week prior to release	Left	5.2 (3.62)	0-10
	Right	5.6 (3.67)	0-10
One week post-release	Left (n=47)	2.9 (2.53)	0-10
	Right (n=45)	3.0 (2.4)	0-9
One month post-release	Left (n=44)	1.5 (1.65)	0-8
	Right (n=43)	1.6 (1.47)	0-7

*Mothers who indicated their infant never latched on to the breast in question, post-release, were not asked to respond to post-release pain questions for said breast

Discussion

The purpose of this study was to learn more about how breastfeeding mothers learned about release of tethered oral tissue(s) in infants and their experiences before and after the surgical process. Mothers in this study reported difficult latching, concerns about infant feeding, and infant fussiness as the most frequent reasons for seeking healthcare provider assistance, reflecting the findings from others exploring the early feeding concerns among breastfeeding mothers (Odom, Li, Scanlon, Perrine, & Grummer-Strawn, 2013; Wagner, Chantry, Dewey, & Nommsen-Rivers, 2013; Colin & Scott, 2002; Chantry, 2011; Feenstra, Jørgine Kirkeby, Thygesen, Danbjørg, & Kronborg, 2018) However, to the best of the authors' knowledge, this was the first study to directly explore these concerns among mothers with infants diagnosed with and surgically treated for 'tongue-tie'.

Using the novel visual tool to identify tissues released, nearly all of the mothers indicated the lingual or labial frenum, or both, were released, while a much smaller number reported release of the buccal frenum. That most reported having more than one tissue released is in contrast to that found by Hale and colleagues (2019), who found this to be the case in only about half of their study population (Hale, Mills, Edmonds, Dawes, Dickson, Barker & Wheeler, 2019) but is similar to that of Caloway and colleagues (2019) who found both the labial and lingual frenum was released in about 74% of their sample (Caloway, Hersh, Baars, Sally, Diercks, & Hartnick, 2019). The relatively low frequency of release of buccal-ties in this sample, and that they were never the only tissue released, is similar to the 5.3% of infants having all three tissues released, reported by Hand and colleagues (Hand, Olivi, Lajolo, Gioco, Marigo, & Castagnola, 2020) in their prospective trial assessing the effect of tissue-release approach on breastfeeding. However, even this relatively low rate of release of the buccal tissues in young infants (e.g., less

than ~12 weeks of age), is not supported by the American Academy of Otolaryngology, as these tissues are unlikely to interfere with the mechanisms required for liquid feeds (Messner, et.al, 2020). Rather it is only after development of rotary chewing, and the need to control semi-solid or solid foods, that anomalies with these tissues would be of concern. Therefore, more education is likely needed in this area.

In general, most mothers in this sample were confident in correctly identifying tissues that were released, felt very involved in the decision to have one or more tissues released, and agreed with the decision to do so. Though accuracy of identification of which tissues were released was not possible using this study design, the high degree of confidence, sense of involvement, and the high percentage of mothers reporting that they self-referred for tissue-release, supports anecdotal reports of some level of consumer-driven involvement.

The lactation consultant, and in particular the IBCLC, was an important information and referral source for mothers in this study. This reinforces the finding by Messner & Lalakea that lactation consultants are more likely than pediatricians to believe tongue-tie to have an impact on feeding (69% vs. 23%, respectively) (Messner & Lalakea, 2000). Though these researchers did not assess actual referral, this finding may indicate an increased likelihood of lactation consultants to refer families to specialized care providers. Another study of mother-infant dyads did find that both lactation consultants and pediatricians were the referral source to a tertiary care setting (Caloway, Hersh, Baars, Sally, Diercks, & Hartnick, 2019). In contrast, other research has found the primary care physician (Bundogji, Zamora, Brigger, Jiang, 2020) or the pediatrician (Unger, et.al., 2019) to be providing the referral for tongue-tie consultations. In fact, Unger and colleagues (2019) found the IBCLC to be the only professional to indicate referring specifically to a pediatrician, so the family could further get referred to an ENT, indicating there are likely to

be multiple professionals involved in the process. Interestingly, some provider-types indicated pediatricians may not be a critical component of the referral pathway (Unger et al, 2019). While this may increase efficiency, the lack of established criteria for assessment and diagnosis, may make this a premature action, if taken. It is likely that until there are established assessment criteria, and a clearly defined scope of practice, involvement of multiple disciplines may decrease the possibility of a missed diagnosis. At the same time, until there is definitive evidence that the procedure(s) improve breastfeeding (e.g., improve inadequate milk-transfer, reduce maternal pain), it is likely that diagnosis and treatment rates will be difficult to interpret. Regardless, because mothers in the present study could indicate more than one source for both information and referral, direct comparison with these current findings is not possible. Perhaps more research could be conducted to further explore referral sources to determine if certain professionals are potentially missing a certain percent of infants or overdiagnosis. Though social media and friends were the second and third most frequently reported sources of information, the cross-sectional nature of this study design does not allow for detection of any relative change in importance of these sources. Future work should further explore these sources, and any changes in relative influence on maternal decision-making.

Mothers in this study reported the provider who performed the intervention was often a pediatric dentist or ENT/otolaryngologist. This finding is similar to the findings of Bundogji, Zamora, Brigger, Jiang (2020), and Patel, Wu, Schwartz, & Rosenfeld (2019) who both evaluated mothers based on referral to an otolaryngologist clinic where the surgical intervention then took place if needed. Furthermore, a study by Hale, Mills, Edmonds, Dawes, Dickson, Barker, and Wheeler (2019) had found that dentists were the most common practitioner to perform procedures, but they did not indicate if they differentiated between a dentist or pediatric

dentist as with the current study. An interesting finding was that four mothers reported the procedure was conducted by an “LC”, with further exploration indicating that at least three of these were identified as holding the IBCLC credential. Though performing release of tethered oral tissues is not within the scope of practice of the practitioner who only identifies as an IBCLC, many IBCLCs maintain one or more credentials, and many of these may well include the procedure in their scope of practice (such as nurse-practitioner, physician, or registered nurse) (Brooks, 2017). Because data-collection did not include assessment of multiple-credentialing, it is not possible to determine the scope of practice of these individuals and it cannot be assumed that they were practicing inappropriately.

There have been many studies that have shown improved maternal nipple pain post-frenotomy with improvements immediately after the procedure as well as up to 2-weeks post-procedure (Hill, Pados, 2020). Results of the current study are in alignment with this prior research. However, no studies, including the present one, have adequately compared breastfeeding pain between those receiving the surgical intervention and those not receiving such an intervention (Walsh & Tunkel, 2018). Therefore, this is a critical area for future research.

Future Studies

There are several areas to explore in this area in future work. First, objective evaluation of the visual identification tool should be conducted, in order to increase validity of its use as a tool. Current referral pathways, including a greater understanding of other credentialing of IBCLCs and scope of practice, should be better defined and optimal pathways identified, should well-designed studies find positive effects of surgical intervention on breastfeeding. Finally, it may be beneficial to conduct qualitative studies, to deepen the understanding of the influence of social media and other factors on the decision to seek tissue-release among breastfeeding mothers.

Limitations

There were several limitations to this study. Because this was a cross-sectional, observational study, and not designed to test relationships between variables, results are only descriptive. However, even if only descriptive, the findings add to what little is known about the maternal experience with breastfeeding an infant diagnosed and surgically treated for “tongue-tie”. The small sample size, lack of homogeneity in terms of maternal race, ethnicity, and marital-and breastfeeding status, and the retrospective nature of the questions each increase the risk of biased results (e.g., selection, social-desirability, and recall bias) and decrease the potential for generalizability. Finally, the visual tool used by mothers to identify the tethered oral tissues needs to be validated against a more objective measure, such as the medical chart. This would increase confidence in use of this measure to assess prevalence in future work. Despite these limitations, this work adds to the literature regarding the maternal experience and provides several potential areas for future exploration.

Conclusion

Mothers reported receiving information from lactation consultants most often, though friends and social media are also important sources. In this sample, referrals are most frequently being made by lactation consultants, though there may be multiple points in the referral pathway, which should be better clarified. Pediatric dentists were most likely to perform the intervention which, given their scope of practice, was an expected finding. However, the finding that IBCLCs may also be performing the intervention requires a better understanding of the multiple-credentialing of practitioners in this field. Pain resolution, post-surgical release of tethered oral tissues, while expected, may not be explained by such intervention and more work is necessary.

Conflicts of Interest

The authors declare no conflicts of interest with respect to this research.

CHAPTER 3: EXPANDED METHODS – PRELIMINARY ANALYSES

Screener/Eligibility

As of 9/24/2020, the day the dataset was closed, there were 479 individuals who had completed the screener and consented to determine eligibility. Of the 479, 206 were ineligible (43% of screens), and 273 were eligible (57% of screens). Reasons that were not mutually exclusive for individuals being ineligible for the study were that the child was older than 12 months (n=133; 64.6% of ineligibles), feeding mode (n=11; 53% of ineligibles), child was not diagnosed with tongue-tie (n=89; 43.2% of ineligibles), and the child was diagnosed, but received no intervention (n=89; 43.2%). Overall, 171 (83%) were ineligible for only 1 reason, 66 (32%) were ineligible for 2 reasons, and 3(1.4%) were ineligible for 3 reasons. Of the 273 that were eligible, 226 (82.8%) were eligible for the surgical version of the survey, and 47 (17.2%) were eligible for the non-surgical version of the survey, all shown in Figure 1.

Surgical Arm. For the surgical arm of the study, there were 226 mothers that were eligible, however, because we were only recruiting 100 mothers per group, as the quota was getting closer to being fulfilled, we closely monitored the number of individuals completing the survey. Once we had reached our quota of 100, we closed down the surgical arm of the survey but for those who still had the survey open when we closed it down, they were able to finish their responses. Therefore, this left us with a total of 116 responses on the surgical arm. For this study's aims, we only wanted to analyze infants that were ≤ 6 months of age, thus had to further clean the data set. From the 116 mothers, a total of 66 were dropped from analysis, where 12 did not complete the survey, 1 did not consent, and 53 had an infant that was > 6 months of age. The total number of responses analyzed from the surgical arm of the survey was a final sample size of 49 mothers, shown in Figure 1.

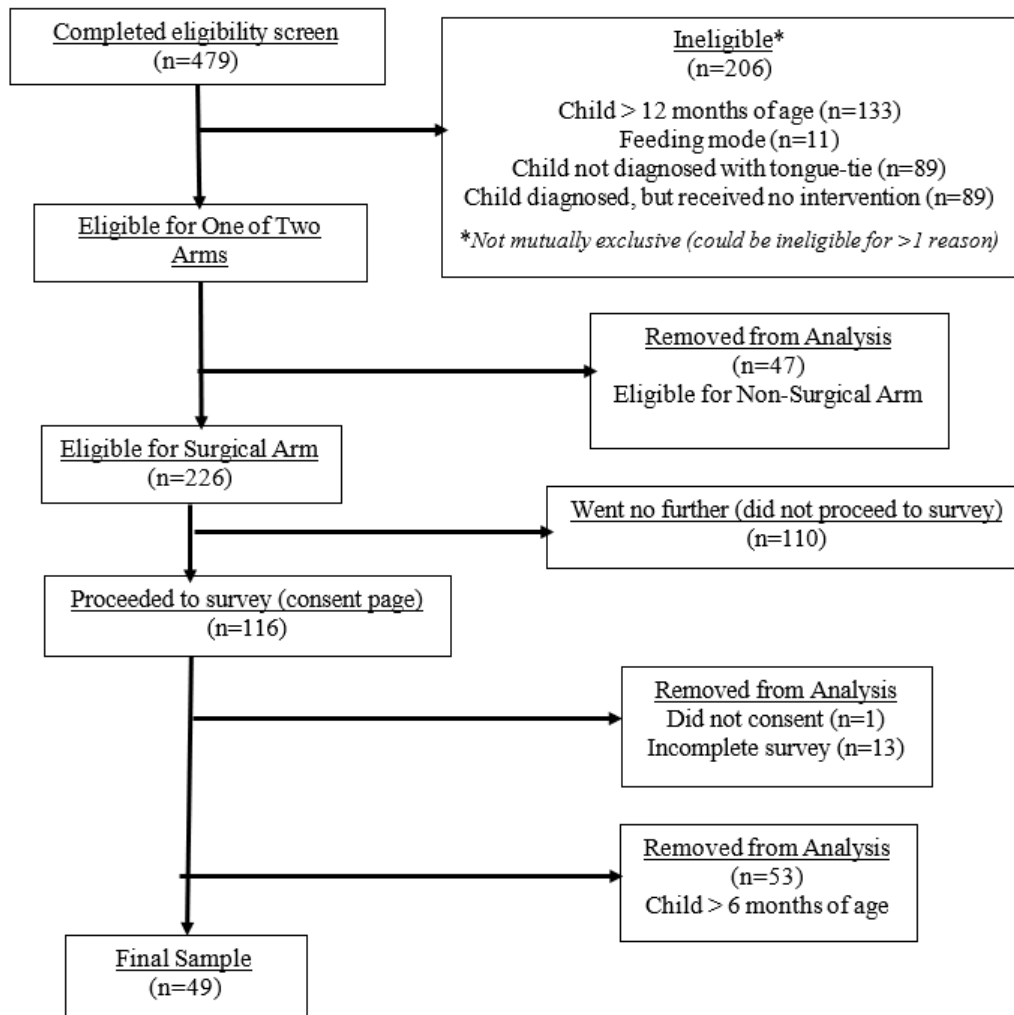


Figure 1. Eligibility Flow Diagram

Non-surgical Arm. For the non-surgical arm of the study, there were 47 mothers that were eligible. However, there were only 17 whom met the criteria for this study and were under 6 months of age and so were not analyzed in this study due too small of a sample size.

Demographic Characteristics

Descriptive statistics were run to assess demographic data among mothers of infants that have been diagnosed with tethered oral tissues and released that tissue via surgical interventions. As shown in Table 9 the group was very homogenous and there were no significant differences among groups that were identified. All variables were assessed for normality before running our statistics. The original plan was to look at change in pain between surgical and non-surgical groups and then compare those results with different demographic variables to see if there were significant difference between certain groups. However, we did not end up assessing change in pain like originally planned and decided to only report descriptive statistics thus did not further analyze change in pain to other variables.

Mothers' Perceptions on Sources of Information

The original table made to report Mothers' Perceptions on Sources of Learning about, Referring to, and Performing Interventions is shown as is in Table 10. Mothers were asked in a multiple choice question who they learned about interventions from, who referred them and who performed the intervention. Each option in the left hand side was given when it could be appropriately listed. If there was a dash mark in any of the rows then either that option was not given for that category (learned from, referred from, or performed), or no one had selected that option. However, as other individuals looked at the table the less and less it made sense to keep the table set up in this format because the dashes got confusing. For this reason, the new tables are split up so each category (learned from, referred from, or performed), have their own tables.

Table 9. Demographic Characteristics of Mothers of Infants Diagnosed with Tethered Oral Tissue Anomalies Resolved via Surgical Intervention (n=49)

Characteristics		N (%)
Maternal Race	White	47 (96)
	Asian	1 (2)
	Middle Eastern	1 (2)
Ethnicity	Hispanic or Latinx	1 (2.0)
	Non-Hispanic or Non-Latinx	47 (95.9)
	Did not respond	1 (2.0)
Maternal Education	High school graduate or equivalent (GED)	4 (8.2)
	Some college, no degree	13 (26.5)
	Associate degree	5 (10.2)
	Bachelor’s degree or higher	27 (55.1)
Marital Status	Single	2 (4.1)
	Married	46 (93.9)
	Divorced	1 (2.0)
Delivery Method	Natural, vaginal Delivery	11 (15.7)
	Medically managed, Vaginal delivery	30 (42.9)
	Medically managed, Cesarean delivery	8 (11.4)
Currently Breastfeeding	Yes	46 (93.9)
	No	3 (6.1)
Current Breastfeeding Behavior	Only Breastfeeding	20 (28.6)
	Only pumped breastmilk	2 (2.9)
	Providing breastmilk at breast or pumped	19 (27.1)
	Feeding at the breast and providing other foods or fluids	3 (4.3)
	Feeding at the breast, providing pumped breastmilk and other foods or fluids	1 (1.4)
Low Income Status ^a	Yes	20 (40.8)
	No	29 (59.2)
		Mean (SD)
Maternal Age (years)		29.5 (4.39)
Infant Birth Weight (lbs)		7.8 (0.97)
Baby Age (months)		3.3 (1.62)

^aCategorized as “low-income” if income-eligible for the Special Supplemental Nutrition Program for Women, Infants, and Children (e.g., WIC), based on 2019-2020 guidelines

Table 10. Mothers' Perceptions on Sources of Learning about, Referring to, and Performing Interventions (n=49)

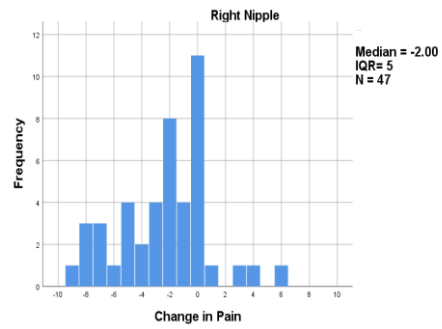
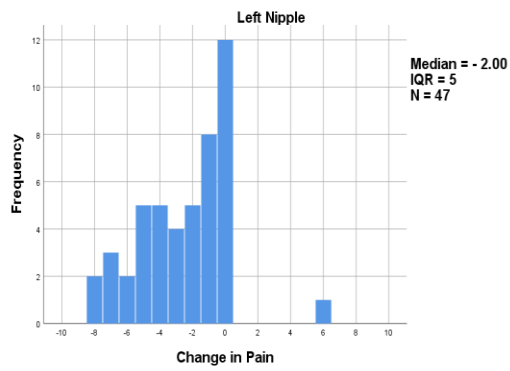
Source	Learning Source n (%)	Referral Source n (%)	Provider Performing n (%)
Doula	1 (2)	2 (4.1)	-
ENT or Otolaryngologist	4 (8.2)	2 (4.1)	9 (18.4)
Family member	3 (6.1)	-	-
Friend	14 (28.6)	-	-
GP/PCP	3 (6.1)	2 (4.1)	1 (2.0)
LC	31 (63.3)	18 (36.7)	4 (8.2)
LC credentials			
CLC	2 (4.1)	2 (4.1)	-
IBCLC	24 (49)	13 (26.5)	3 (6.1)
WIC peer counselor	1 (2.0)	-	-
Community support individual	-	1 (2.0)	-
Unsure	4 (8.2)	2 (4.1)	1 (2.0)
Midwife	5 (10.2)	3 (6.1)	-
Nurse	4 (8.2)	-	1 (2.0)
OT	3 (6.1)	1 (2.0)	-
Pediatrician	10 (20.4)	15 (30.6)	3 (6.1)
Pediatric chiropractor	2(4.1)	1 (2.0)	-
Pediatric dentist	12(24.5)	3 (6.1)	28 (57.1)
Social media	13(26.5)	-	-
SLP	2(4.1)	1 (2.0)	-
Self-research	3(6.1)		-
Self-referred	-	16 (32.7)	-
From previous experience	2(4.1)		-
Did not need a referral	-	1 (2.0)	-
Oral and maxillofacial surgeon	-	-	4 (8.2)
Periodontist	-	-	1 (2.0)

*Mothers could select all that apply for each of the categories

Changes in Maternal Nipple Pain

When assessing maternal nipple pain the goal was to first look at differences in changes in pain between mothers whose infants had released tethered oral tissues via a surgical intervention to mothers whose infants pursued non-surgical interventions. To do this we collected data on pain the week prior to the intervention, the week after intervention, and the month after the intervention. However, in this study we did not have enough mothers in the non-surgical group, so we did not end up being able to compare the two groups of mothers. Instead we ran statistics to look at change in pain in only the surgical group of mothers and assessed to see if there was long term change over time. Numbers are reported as means and interquartile ranges because the change in pain variables were not normally distributed so nonparametric statistics were used (see Figure 2 and Table 11).

a. Change in Pain the week prior to the Intervention to the week after



b. Change in Pain the week prior to the Intervention to the month after

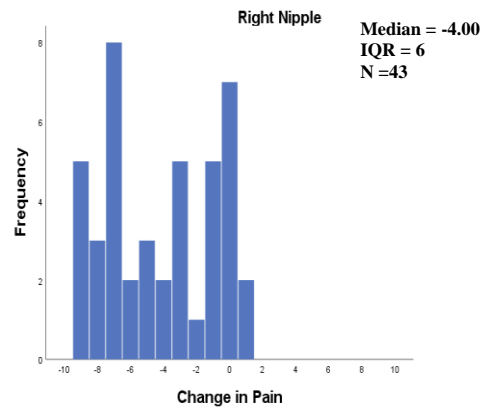
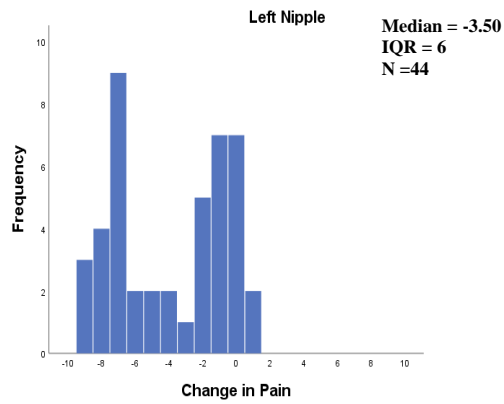


Figure 2. Changes in Maternal Nipple Pain

Table 11. Perceived Maternal Left and Right Nipple Pain Before and After Tissue Release

	N	Median	IQR
Left nipple pain the week before intervention	49	5.00	8
Right nipple pain the week before intervention	49	7.00	8
Left nipple pain the week after intervention	47	1.00	4
Right nipple pain the week after intervention	45	2.00	4
Left nipple pain the month after intervention	44	1.00	1
Right nipple pain the month after intervention	43	1.00	1

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APPENDIX – FULL SURVEY

1. What is your date of birth? (MM/DD/YYYY)
2. What is your baby's date of birth? (MM/DD/YYYY)
3. How much did your baby weigh at birth? (pounds, ounces)
4. Which of these best describes how your baby was delivered?
Natural, vaginal delivery (no IV medication or epidural)
Medically managed, vaginal delivery (e.g., interventions such as IV medication(s), epidural)
Medically managed, cesarean delivery (e.g., interventions such as IV medication(s), epidural)
Other (please briefly describe): _____
5. Was your baby born prematurely?
Yes
No
Unsure
6. How premature was your baby? (i.e., What was their gestational age?)
less than 28 weeks
28 to 32 weeks
32 to 37 weeks
Unsure
7. Are you currently breastfeeding/chestfeeding/providing pumped breastmilk to your baby?
Yes
No
8. Please select which best describes your current breastfeeding/chestfeeding behavior:
I am only breastfeeding/chestfeeding (no other foods or fluids, except for medications)
I am providing only pumped breastmilk (no other foods or fluids, except for medications)
I am providing only breastmilk (pumped or at the breast; no other foods or fluids, except for medications)
I am feeding at the breast/chest and providing other foods/fluids such as infant formula and/or solid foods
I am giving pumped breastmilk and providing other foods/fluids such as infant formula and/or solid foods
I am feeding at the breast/chest, providing pumped breastmilk, and providing other foods/fluids such as infant formula and/or solid foods
Other (please briefly describe):_____

9. How long did you breastfeed/chestfeed/provide pumped breastmilk to your baby?

< 1 day

a few days (< 1 week)

1 – 2 weeks

3 – 4 weeks

1-2 months

3 – 4 months

5 – 6 months

> 6 months

Other (please briefly describe): _____

10. Including this baby, how many children do you have?

1

2

3

4 or more

11. Did you breastfeed any of your other children?

Yes

No

12. Which of the following statements best describes your prior experience with breastfeeding?
(please choose only one)

It was a great experience (experienced no problems and/or it lasted as long as I wanted it to)

It was a good experience (experienced no major problems and/or it lasted as long as I wanted it to)

It was an average experience (experienced one major problem and/or it ended before I wanted it to)

It was a bad experience (experienced one or more major problems and/or it ended long before I wanted it to)

I had a terrible experience (experienced several major problems and/or it ended long before I wanted it to)

Other (please briefly describe): _____

13. Please enter your zip code: _____

14. What is your race? (Click all that apply).

White

Black or African American

American Indian or Alaska Native

Asian

Native Hawaiian or Pacific Islander

Choose not to respond

Other (please briefly describe): _____

15. What is your ethnicity?

Hispanic or Latinx

Non-Hispanic/Latinx

Choose not to respond

16. What is the highest degree or level of school you have completed?

Multiple categories provided

17. What is your marital status?

Single, never married

Married or domestic partnership

Widowed

Divorced

Separated

Choose not to respond

Other (please briefly describe)_____

18. Do you participate in WIC (The Special Supplemental Nutrition Program for Women, Infants, and Children)?

Yes

No

Unsure

Prefer not to respond

19. What is your current household size?

Response options from 2 to more than 8

20. Is your annual income less than, equal to, or more than \$31,894?

More than

Equal to

Less than

21. Is your annual income less than, equal to, or more than \$40,182?

More than

Equal to

Less than

22. Is your annual income less than, equal to, or more than \$48,470?

More than

Equal to

Less than

23. Is your annual income less than, equal to, or more than \$56,758?

More than

Equal to

Less than

24. Is your annual income less than, equal to, or more than \$65,046?

More than

Equal to

Less than

25. Is your annual income less than, equal to, or more than \$73,334?

More than

Equal to

Less than

26. Is your annual income less than, equal to, or more than \$81,622?

More than

Equal to

Less than

27. Is your annual income less than, equal to, or more than \$89,910?

More than

Equal to

Less than

28. Do you receive SNAP benefits? (Formerly known as Food Stamps)

Yes

No

Unsure

Prefer not to respond

29. Please select any of the following reasons you sought assistance from healthcare provider(s) for your child diagnosed with issues with tethered oral tissues (check all that apply):

Excessive fussiness

Excessive crying

Difficulty latching

Concerns about weight gain (gaining too slowly)

Concerns about weight gain (gaining too quickly)

To improve feeding

To improve speech

Unsure

Other _____

30. In the previous question, you selected "improve feeding" as a reason for seeking assistance. Was this liquid feeding (i.e., breastfeeding/chestfeeding/pumped milk or formula) or solid feeding (i.e., solid foods)?

Liquid

Solid

Both liquid and solid

On the following screens, please indicate which of your child's tissue(s) was/were clipped/lasered by answering the questions after each drawing.

[tongue-tie drawing]

31. Was this tissue, highlighted in the drawing, clipped/lasered?

Yes, it was clipped

Yes, it was lasered

No, it was not clipped or lasered

Unsure

32. How confident are you in your response to the previous question?

Not confident at all

Not confident

Neutral

Confident

Very confident

[lip-tie drawing]

33. Was this tissue, highlighted in the drawing, clipped/lasered?

Yes, it was clipped

Yes, it was lasered

No, it was not clipped or lasered

Unsure

34. How confident are you in your response to the previous question?

Not confident at all

Not confident

Neutral

Confident

Very confident

[cheek-tie drawing]

35. Was this tissue, highlighted in the drawing, clipped/lasered?

Yes, it was clipped

Yes, it was lasered

No, it was not clipped or lasered

Unsure

36. How confident are you in your response to the previous question?

Not confident at all

Not confident

Neutral

Confident

Very confident

37. Please check any of the following activities your child was involved in **before** any tissues were clipped/lasered (check all that apply):

*Feeding/swallowing therapy (ex., with an OT, PT, or SLP)**

Breastfeeding latch assessment

Speech therapy

Other therapeutic exercises (ex. Craniosacral therapy)

Other (please describe) _____

**OT=Occupational Therapist; PT=Physical Therapist; SLP=Speech Language Pathologist*

38. How long ago was/were the clipping/lasering procedure(s) done?

Less than 1 week ago

More than a week, but less than 2 weeks ago

More than 2 weeks, but less than 3 weeks ago

More than 3 weeks, but less than 4 weeks ago

More than 4 weeks ago

Unsure

Other (please describe): _____

39. How did you learn* about clipping/lasering procedure(s)? (check all that apply)

**This question is just asking for any sources of information about the procedure. We will ask about who referred you for this procedure in the next question.*

Doula

ENT/Ear, Nose, & Throat Otolaryngologist

Family member

Friend

Gastrointestinal Doctor

General Practitioner (GP)/Primary Care Physician (PCP)/Family Physician

Lactation Professional

Midwife

Nurse

OT/Occupational Therapist

Pediatrician

Pediatric chiropractor

Pediatric dentist

Social media

SLP/Speech-Language Pathologist

Unsure

Other (please describe) _____

40. You selected "Lactation Professional" as a way you learned about clipping/lasering procedure(s). Please select that person's credentials, if known (please select only one):

CLC/Certified Lactation Consultant

CLE/Certified Lactation Educator

CLS/Certified Lactation Specialist

Community Support Person (i.e., La Leche League Leader, Baby Café Leader)

IBCLC/International Board Certified Lactation Consultant

LC/Lactation Consultant

WIC Peer Counselor

Unsure

Other: _____

41. Who referred you for the clipping/lasering procedure(s)? (check all that apply)

Doula

ENT/Ear, Nose, & Throat Otolaryngologist

Gastrointestinal Doctor

General Practitioner (GP)/Primary Care Physician (PCP)/Family Physician

Lactation Professional

Midwife

Nurse

OT/Occupational Therapist

Pediatrician

Pediatric chiropractor

Pediatric dentist

Self

SLP/Speech-Language Pathologist

Unsure

Other: _____

42. You selected "Lactation Professional" as someone who referred you for the clipping/lasering procedure(s). Please select that person's credentials, if known (please select only one):

CLC/Certified Lactation Consultant

CLE/Certified Lactation Educator

CLS/Certified Lactation Specialist

Community Support Person (i.e., La Leche League Leader, Baby Café Leader)

IBCLC/International Board Certified Lactation Consultant

LC/Lactation Consultant

WIC Peer Counselor

Unsure

Other: _____

43. Who performed the clipping/lasering procedure(s)?

- Doula*
- ENT/Ear, Nose, & Throat Otolaryngologist*
- Gastrointestinal Doctor*
- General Practitioner (GP)/Primary Care Physician (PCP)/Family Physician*
- Lactation Professional*
- Midwife*
- Nurse*
- OT/Occupational Therapist*
- Pediatrician*
- Pediatric chiropractor*
- Pediatric dentist*
- SLP/Speech-Language Pathologist*
- Unsure*
- Other: _____*

44. You selected "Lactation Professional" as someone who performed the clipping/lasering procedure(s). Please select that person's credentials, if known (please select only one):

- CLC/Certified Lactation Consultant*
- CLE/Certified Lactation Educator*
- CLS/Certified Lactation Specialist*
- Community Support Person (i.e., La Leche League Leader, Baby Café Leader)*
- IBCLC/International Board Certified Lactation Consultant*
- LC/Lactation Consultant*
- WIC Peer Counselor*
- Unsure*
- Other: _____*

45. How involved did you feel in the decision to have your child undergo the clipping/lasering procedure(s)?

- Very involved*
- Somewhat involved*
- Neither involved nor uninvolved*
- Not very involved*
- Not involved at all*

46. How much did you agree, or disagree, with the decision to have your child undergo the clipping/lasering procedure(s)?

- Strongly disagreed*
- Somewhat disagreed*
- Neither disagreed nor agreed*
- Somewhat agreed*
- Strongly agreed*

47. What do you believe was the purpose of the clipping/lasering procedure(s)? (check all that apply):

To improve feeding

To improve speech

Unsure

Other (please describe) _____

48. How was this/were these tissue(s) cut? (check all that apply)

Using a laser

Using scissors

Unsure

Other (please describe) _____

49. Where did this/these procedure(s) occur?

In a medical professional's office

In a hospital setting

At home

Unsure

Other (please describe) _____

50. Did this/these procedure(s) require stitches?

Yes

No

Unsure

Other (please describe) _____

51. Please select any of the following symptoms your child experienced during, or immediately following,* this/these procedure(s): (check all that apply)

Excessive fussiness

Excessive crying

Excessive bleeding

Difficulty latching

Unsure

Other (please describe) _____

**within the first hour*

52. Thinking of the time during and immediately after* the procedure was performed, how difficult do you believe this was for your child?

Very difficult

Somewhat difficult

Neutral

Not very difficult

Not difficult at all

**within the first hour*

53. Using the dials, please indicate how painful you believe the procedure(s) was/were for your child:

	Least painful					Most painful				
	1	2	3	4	5	6	7	8	9	10
How painful was this for your child?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

54. Has your child fully recovered from the/these procedure(s)?

Yes

No

Unsure

55. Please briefly explain why you feel this way.

56. If not mentioned in your previous response, did your child have any of the following in the week following the procedure(s)? (check all that apply)

Difficulty feeding at the breast/latching

Difficulty feeding by bottle

Completely refused to eat

Difficulty sleeping

My child did not experience any of these problems

Other _____

57. Were you billed, or was your insurance billed, for this/these procedure(s)?

Yes

No

Unsure

Other (please describe) _____

58. Following this/these procedures did feeding improve?

Yes

No

Not applicable

Other (please describe) _____

60. Following this/these procedure(s) did speech improve?

Yes

No

Not applicable

Other _____

61. Please check any of the following activities your child was involved in **after** the clipping/lasering procedure(s) (check all that apply):

Feeding/swallowing therapy (ex., with an OT, PT, or SLP)

Breastfeeding latch assessment

Speech therapy

Other therapeutic exercises (ex. Craniosacral therapy)

Other _____

62. Using the dials, please indicate the level of pain, if any, you experienced in your **LEFT** nipple when breastfeeding/chestfeeding, **in the week before** the clipping/lasering procedure:

	Least pain					Most pain				
	1	2	3	4	5	6	7	8	9	10
LEFT nipple	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

63. Using the dials, please indicate the level of pain, if any, you experienced in your **RIGHT** nipple when breastfeeding/chestfeeding, **in the week before** the clipping/lasering procedure:

	Least pain					Most pain				
	1	2	3	4	5	6	7	8	9	10
RIGHT nipple	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

64. Using the dials, please indicate the level of pain, if any, you experienced in your **LEFT** nipple when breastfeeding/chestfeeding, **one week after** the clipping/lasering procedure:

	Least pain					Most pain				
	1	2	3	4	5	6	7	8	9	10
LEFT nipple	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

65. Please click here if your child never successfully latched to the **LEFT** breast, post-procedure

My child never successfully latched to the LEFT breast, post-procedure

66. Using the dials, please indicate the level of pain, if any, you experienced in your **RIGHT** nipple when breastfeeding/chestfeeding, **one week after** the clipping/lasering procedure:

	Least pain					Most pain				
	1	2	3	4	5	6	7	8	9	10
RIGHT nipple	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

67. Please click here if your child never successfully latched to the **RIGHT** breast, post-procedure

My child never successfully latched to the RIGHT breast, post-procedure

68. Using the dials, please indicate the level of pain, if any, you experienced in your **LEFT** nipple when breastfeeding/chestfeeding, **one month* after** the clipping/lasering procedure:

	Least pain					Most pain				
	1	2	3	4	5	6	7	8	9	10
LEFT nipple	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**If it has not yet been a month, answer based on level of pain experienced TODAY.*

69. Using the dials, please indicate the level of pain, if any, you experienced in your **RIGHT** nipple when breastfeeding/chestfeeding, **one month* after** the clipping/lasering procedure:

	Least pain					Most pain				
	1	2	3	4	5	6	7	8	9	10
RIGHT nipple	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

**If it has not yet been a month, answer based on level of pain experienced TODAY.*

70. Did the procedure(s) to clip/laser one or more tethered oral tissues help you meet your breastfeeding goals?

Yes

No

Unsure

Other _____

71. Did any of the clipped/lasered tissue(s) grow back?

Yes

No

Unsure

72. Was/were the tissue(s) re-clipped/re-lasered?

Yes

No

Unsure

Other _____

73. Has your child had any other oral surgeries?

Yes

No

74. Please select any of these issues your child may have had that required surgery (check all that apply):

Tonsils

Adenoids

Cleft lip and/or palate

Craniofacial abnormalities

Other) _____

75. When did these surgery/surgeries occur?

Less than 1 week ago

More than a week, but less than 2 weeks ago

More than 2 weeks, but less than 3 weeks ago

More than 3 weeks, but less than 4 weeks ago

More than 4 weeks ago

Unsure

Other _____

76. How did you learn* about clipping/lasering procedure(s)? (check all that apply)

**This question is just asking for any sources of information about the procedure. We will ask about who referred you for this procedure in the next question.*

Gastrointestinal Doctor

Friend

ENT/Ear, Nose, & Throat Otolaryngologist

Family member

Doula

Lactation Professional

SLP/Speech-Language Pathologist

Social media

Nurse

General Practitioner (GP)/Primary Care Physician (PCP)/Family Physician

OT/Occupational Therapist

Pediatrician

Pediatric dentist

Pediatric chiropractor

Midwife

Unsure

Other (please describe) _____

77. You selected "Lactation Professional" as a way you learned about clipping/lasering procedure(s). Please select that person's credentials, if known (please select only one):

CLC/Certified Lactation Consultant

CLE/Certified Lactation Educator

CLS/Certified Lactation Specialist

Community Support Person (i.e., La Leche League Leader, Baby Café Leader)

IBCLC/International Board Certified Lactation Consultant

LC/Lactation Consultant

WIC Peer Counselor

Unsure

Other: _____

78. What do you believe was the purpose of the clipping/lasering procedure(s)? (check all that apply):

To improve feeding

To improve speech

Unsure

Other (please describe) _____

79. You are nearly finished! Is there anything else you think we should know about your experience? If so, please tell us about that here:

VITA

Taylor grew up in Manitowoc, Wisconsin and continued to pursue her education at Western Illinois University. From Western Illinois University she graduated with a Bachelor of Science with dual degrees in Dietetics and Exercise Science. Her passion for nutrition and living a healthy lifestyle was borne out of her experience as a competitive swimmer when she ultimately realized nutrition played a key role in enhancing performance, especially while participating in college athletics. Taylor continued her education at the University of Tennessee where she will graduate with a Master of Science degree in Nutrition with a concentration in Public Health Nutrition in Summer 2021. Along with the Master's program, Taylor will also complete the University of Tennessee Dietetic Internship during Spring and Summer semesters of 2021. During her time at the university she was also a graduate teaching assistant and was involved in the I-CAN THRIVE research lab. She will sit for the Registration Examination for Dietitians after graduation.