

The Truth about TOTs: Unpacking the controversies of diagnostics, treatment and impact
of tethered oral tissues

by

Mary Miller

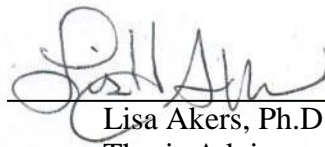
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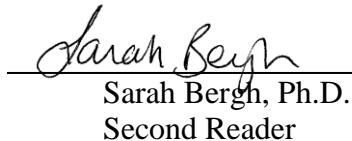
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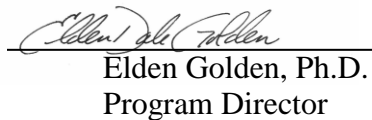
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Lisa Akers, Ph.D.
Thesis Advisor

12/31/2018
Date


Sarah Bergh, Ph.D.
Second Reader

12/31/2018
Date


Elden Golden, Ph.D.
Program Director

12/31/2018
Date

ABSTRACT

An abstract of the thesis of Mary Miller for the Master of Arts degree, Union Institute & University, December 2018.

Title: The Truth about TOTs: Unpacking the controversies of diagnostics, treatment and impact of tethered oral tissues

Ankyloglossia, commonly called tongue-tie, has been a source of debate among medical professionals for centuries. There is no universally agreed upon diagnostic criteria, revision technique or parameters for determining whether the revision was a success. Areas impacted by tongue-tie include the ability to suck, swallow, and breathe. Airway restrictions can cause troubles with disordered breathing, leading to postural changes, autoimmune dysfunction and bodily inflammation, subsequent behavioral and educational deficits and their resulting social impacts such as postpartum mental health struggles and family stress. This research shows that not only are healthcare providers assessing for TOTs without using screening tools, but many have never received formal instruction on the subject. Those who have been trained are still frequently lacking in evidence-based knowledge about TOTs and their physiological impacts. More data is needed to ascertain best practices regarding diagnosis and revision of TOTs.

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Chapter 1: Introduction

The accepted prevalence of tongue-tie, known within the medical community as ankyloglossia, is 2%-5% of our population (Power & Murphy, 2015) and it is genetically inherited (Han, Kim, Choi, Lim & Han, 2012). However, as medical professionals are in contentious disagreement about the diagnostic criteria to determine what conditions constitute ankyloglossia¹, and indeed, whether it impacts the breastfeeding dyad at all (Evans, 2008), the rate of ankyloglossia may be much higher. This disagreement within various fields of professionals might result in missed diagnoses, presenting a uniquely devastating circumstance for the breastfeeding relationship between mother and infant.

Agilos, meaning *curved*, and *glossa*, meaning *tongue*, are the two Greek words at the root of the term *ankyloglossia* (Suter & Bornstein, 2009, pg. 1204). This condition is present when the lingual frenum (or frenulum), which is a small band of tissue connecting the underside of the tongue to the floor of the mouth, restricts tongue movement (Johnson, 2006, pg. 96). "Efficient breastfeeding, relies on the baby having an adequate length of free tongue tip, having adequate overall tongue movement, and also having sufficient flexibility of the floor of the mouth" (Johnson, 2006, pg. 97). This is important for an effective latch and milk transfer. When a breastfeeding mother has a baby whose tongue is restricted, it can become extremely painful to nurse the infant. The baby can also have difficulty removing enough milk from the mother's breast to sustain growth.

¹For further reading on the disagreement regarding diagnostic criteria for ankyloglossia: Douglas, 2017b; Douglas, 2017c; Segal, Stephenson, Dawes, Feldman, 2007

History and Background

The recommendation to incise a restrictive frenulum has not yet come full circle from where it began. When breastfeeding was considered critical for life as babies were once wholly dependent upon breastfeeding for survival, it was a normal part of the medical recommendations. Tongue tie and frenotomies have been discussed in the literature since biblical times, including mentions in Greek medicine in the first, second and third centuries AD. From 1100 AD through the present, there has been much controversy around which helping profession would be better suited to perform frenotomies (Obladen, 2010). In fact, from the 16th-18th centuries, Spanish medical text recommendations for diagnostic screening and revision for tongue ties are comparable to today's accepted recommendations (i.e. to perform a frenotomy in the event of breastfeeding or speech difficulties). This controversy continues today, albeit with more professional fields involved as the practice of medicine has modernized.

In the 18th century, a British surgeon named Dr. William Moss wrote that tongue ties were commonly treated immediately upon their noticed interference with breastfeeding (as cited in Griffiths, 2004). As time progressed and bottle-feeding formula became more common and viewed as an equally healthy alternative for breastfeeding, the association between ankyloglossia and nursing appeared to become weaker. Women perhaps gave up breastfeeding more readily when it was painful and chose to bottle feed instead. At this point the recommendation to perform frenotomies virtually disappeared from the literature, as it was no longer considered a matter of medical necessity. The scholars of the time in fact specifically stated at this point (around the time of the second World War) that ankyloglossia did not interfere with breastfeeding, and the routine

treatment of ankyloglossia was removed from medical recommendations (Griffiths, 2004).

Current state of the problem

Unfortunately for babies and mothers who want to breastfeed, a diagnosis of tongue-tie is likely to be even more impactful on their lives today. Despite numerous studies showing that ankyloglossia can, in fact, interfere with breastfeeding and can be very safely, quickly and easily treated,² both the American Academy of Pediatrics and the Canadian Paediatric Society issued statements in 2010 and 2011, respectively, and neither came out with a particularly strong statement in favor of frenotomy for ankyloglossia when breastfeeding difficulties are present (as cited in Ito, 2014). One begins to wonder why such major pediatric institutions are reluctant to accept the available literature which clearly shows that many breastfeeding relationships could be saved with frenotomy. The answer seems to be the vehement disagreement among industry professionals surrounding nearly every aspect of tongue restriction.³

It seems that many (but not all) lactation consultants are referring clients for frenotomies, however other providers do not seem to recognize ankyloglossia when it is present or do not think its treatment is necessary or warranted (Edmunds, Fulbrook, & Miles 2013). This subsequently binds the lactation consultant's hands, as exclusive

² For further reading on the impacts of ankyloglossia on breastfeeding and its treatment: Ballard, Auer, & Khoury, 2002; Buryk, Bloom & Shope, 2011; Fernando, 1998; Genna, 2017; Hazelbaker, Baeza, Genna, Murphy, Kaplan, Douglas, Martinelli, Marchesan, & Smillie, 2017; Kotlow, 2011; Edmunds, Fulbrook & Miles, 2011; Edmunds, Fulbrook & Miles, 2013; Cho, Kelsberg, & Safranek, 2010; Forelza, Black, McNamara, & Sullivan, 2010; Ito, 2014; Moss; 1794; Segal, Stephenson, Dawes & Feldman, 2007; Todd, 2014; Puapornpong, Raungrongmorakot, Mahasitthiwat, Ketsuwan, 2014.

³ For further reading on the controversies surrounding ankyloglossia: Douglas, 2017a; Douglas 2017b; Douglas, 2017c; Evans, 2008; Ghaheri & Cole 2017; Messner, & Lalakea, 2000; Smyth, 2015

breastfeeding with restrictive ankyloglossia can sometimes lead to breastfeeding failure in a best-case scenario, or failure to thrive in infants in a worst case (Forlenza, Black, McNamara, & Sullivan, 2010).

Perspectives on whether or how to assess and treat ankyloglossia are plentiful and conflicting. Cockley and Lehman (2015) state,

One of the barriers to diagnosing tongue-tie is the lack of consensus on how it should be evaluated. There exists no clear, measurable standardization for tongue-ties. Classifications could guide us in assessing severity, favoring a more uniform documentation of incidence, treatment plans and outcomes. Currently, different professions are using their own means of assessment with little consistency. Unfortunately, due to this lack of uniformity, an accurate statistical incidence of ankyloglossia is difficult to determine. Until a standardized assessment protocol is adopted, it is unlikely that we will have generally accepted statistics (pg. 18).

The disagreement about what ankyloglossia is, whether it is present, and whether it should be treated at all, seems incongruous with the plethora of data in existence. There is near-universal agreement among the current data indicating that frenotomies, as they are currently being performed, are of minimal risk and quite effective in resolving a myriad of breastfeeding issues, including maternal nipple pain, infant milk transfer and intake, secondary maternal low milk supply, and many more.⁴ What is not agreed upon,

⁴ For further reading on the safety of frenotomies: Cho, Kelsberg, & Safraneck, 2010; Edmunds, Miles, & Fulbrook, 2011; Edminds, Miles, & Fulbrook 2013; Ito, 2014; Segal et al., 2007; Todd, 2014

or even discussed within the literature, is not only how a frenotomy should be performed, but that there is no established standard by which to judge the efficacy of tongue tie treatment with regard to long-term outcomes beyond breastfeeding success.

Another concern not well-represented in the current literature is the variability in fields of research in which data on ankyloglossia are found. It seems unlikely that a pediatrician, for example, is going to be reading otolaryngology journals, or that a lactation consultant is going to be reviewing research from speech-language pathology journals. With ankyloglossia touching so many fields of study, it makes sense that those looking at data from only their own professional field will have a myopic view of ankyloglossia's impacts, missing the bigger picture and indeed, a more holistic view of its impacts upon people in all walks of life.

If one accepts that 2-5% of babies experience ankyloglossia (remembering that this figure is likely to be quite low due to the disagreement on diagnostic criteria), it is no wonder there is such a high rate of breastfeeding cessation. Roughly 80% of mothers in the US start off breastfeeding their newborns, though less than half of those are still breastfeeding at all by six months of life and just over a quarter are still breastfeeding at the end of the baby's first year (CDC, 2014). These low success rates indicate that there is something very, very wrong with the availability of quality breastfeeding support within the United States.

Purpose and Potential Value of this Research

This thesis project will explore the controversy within the field of lactation and some early childhood therapeutic and medical professions about ankyloglossia. Also

explored will be the ways in which this controversy impacts professional practice today, and its subsequent consequence on the nursing dyad and indeed, anyone with a tongue-tie. This controversy has led to widespread confusion about what constitutes ankyloglossia and what, if anything, should be done about it. The conflict and confusion among professionals can make it very challenging for parents and families of the breastfed infant to decide what to do if they suspect ankyloglossia may be present, and to whom they should turn for help.

The primary research project contained within this thesis was intended to compare the agreement or disagreement among the most commonly used diagnostic tools and their efficacy on breastfeeding success for babies with tongue ties, compared with the breastfeeding success of babies who are found not to have tongue tie. Further, a discussion of whether the fact that ankyloglossia is being screened for at all, and then whether the choice in assessment tool impacts the success of the breastfeeding dyad will follow.

A second research project was undertaken to assess the level of education, knowledge, attitudes and practices regarding ankyloglossia among providers within whose scope of practice it is to assess infants' anatomy and function. The implications of this information are explored, and recommendations made for future practice.

Recognizing that the basis of the ethical practice of medicine is upon informed consent on the part of the patient, the key question considered is whether parents of tongue-tied children are given the opportunity to fully consent to revise (or not revise) a tongue tie. Further, does the training (or lack thereof) on how to properly utilize these tools by the industry professionals who may be utilizing them impact their efficacy? This

information should help providers learn which tools are effective or equivalent and will assist parents in making an informed choice for treatment when their children are found to have ankyloglossia.

Chapter 2: Review of the Literature

TOTs basics

Tongue-tie is diagnosed when the thin tissue connecting the tongue to the bottom of the mouth is overly thickened, short, or attached too far towards the tip (anterior) of the tongue to allow for proper functional movement, including the ability to move the tongue in and out and/or up and down within the mouth (Hazelbaker, 2011). Tongue tie can cause difficulties with breastfeeding, inhibit speech, and even cause difficulties kissing and interfere with sexual relationships later in life (Messner & Lalakea, 2000, Fernando, 1998). However, medical professionals are in disagreement about diagnostic criteria for ankyloglossia (Douglas, 2017b; Douglas, 2017c; Segal, Stephenson, Dawes, & Feldman, 2007) and whether it impacts the breastfeeding dyad at all (Evans, 2008). This controversy within the field might result in missed diagnoses, presenting a uniquely devastating circumstance for the breastfeeding mother and infant.

A detailed case study involving ultrasound data to observe tongue movements, measured milk transfer, and vacuum suction in the mouths of a small sample of infants, found a wide variety of vacuum levels as well as reported milk intake (Geddes, Kent, McClellan, Garbin, Chadwick & Hartmann, 2010). This study also showed that nipple compression that occurred when a baby had a tongue tie was normalized post-frenotomy. Geddes et al (2010) theorized that in babies whose ankyloglossia does impact breastfeeding, “abnormal compression of the nipple may result in an ineffective suck by mechanically compressing the milk ducts in the nipple, obstructing the milk flow and

thus reducing milk intake” (p. 303). This means that a baby may have a reduced ability to transfer milk at the breast regardless of whether any breastfeeding problems had been identified; it helps to explain why babies whose mothers have a rapid letdown (therefore making milk transfer quite easy for the restricted infant) may still gain weight appropriately while tied. The largest study done to date of infants with tongue-tie showed that they had an easily “identifiable group of symptoms (poor latch, nipple trauma, and continuous feeding) that prevented them from breastfeeding” (Griffiths, 2004 p. 413).

A Note on Labial and Buccal Ties

Labial (lip) and buccal (cheek) ties are even more controversial than tongue ties and remain relatively unstudied in the literature. Perhaps more interestingly, the subject of lip ties has been a controversy for just as long as tongue ties; for at least several hundred years of recorded history, providers have been in disagreement about whether and how to incise the frenum (Romero-Maroto & Sáez-Gómez, 2012). These types of ties are considered (by those who believe they exist) to occur when the frenulum in these areas, if present, is overly short or taught and is impacting function in some way (Kotlow, 2010, 2011, 2013, 2017, 2018; Ghaheri & Cole, 2017; Macaluso & Hockenbury, 2015). Indeed, Dr. Kotlow has also created a set of diagnostic criteria to identify and classify lip ties as well, indicating that the possibility of their impact on breastfeeding in combination with the increased risks of dental caries justify a division of these tissues if symptoms are present (2017).

However, there are also industry professionals who claim that lip and buccal ties are a figment of the imagination of those who do not know how to competently support a dyad through the breastfeeding experience, as there is no empirical evidence to support

their clinical significance (Hazelbaker, 2018, Douglas 2017a, 2017b). Such strong statements in opposition to the notion of buccal and upper lip ties are made to specifically state that these frena do not impact function in any way of the breastfeeding infant, as the infant has no need to flange his or her upper lip but needs only to avert it, with the seal of the mouth being made by the lower lip during breastfeeding (ACIOR, 2018, Douglas 2017a).

Available Diagnostic Assessment Tools for Ankyloglossia

There are several diagnostic tools to assess for ankyloglossia in newborns. The HATLFF is the most researched tool described in the literature (Roberta Lopes de Castro, Irene Queiroz, José Roberto, Heitor Marques, Reinaldo Jordão & Giédre, 2016) and was developed by Dr. Alison Hazelbaker, IBCLC in 1993. This tool is usually utilized with breastfeeding infants. The next most commonly found tool within the literature was created by Dr. Larry Kotlow (2016) and is based on his decades of pediatric dental work and ankyloglossia research, which he published most recently in his book *SOS 4 TOTS*. His criteria tend to be utilized more by medical professionals such as dentists, otolaryngologists, orthodontists, and others.

Dr. Kotlow's assessment contains a 4-point scale, with class 1 being the least severe (and posterior) and a class 4 being the most severe (anterior). Class 1 ties are considered submucosal (and are therefore difficult to see), where the frenulum is "located from the base of the tongue halfway to the salivary duct" and the class 4 ties "located at the tip of the tongue and extending halfway between the salivary duct and the tip of the tongue. The decision to perform a frenotomy is on function and appearance, but the classifications are in appearance only (Kotlow, 2016).

Hazelbaker's assessment tool is focused on function over appearance (though both are assessed and scored) and is generally favored among professionals due to its evidence-based nature and high level of reliability. Amir et al. (2006) assessed the HATLFF for reliability and found that just the first three function items (lift of tongue, lateralization, and extension of tongue) were more vital to diagnosis than the four function items related to sucking (cupping, spread, snapback and peristalsis) (Amir, James & Donalith 2006).

Less frequently discussed in the literature but still used by professionals is the Coryllos Classification Scale (Coryllos, Genna & Salloum (2004), which is similar to Kotlow's in that the scale is descriptive of the location on the tongue in which the frenum connects, but whose numbers run in the opposite direction, with a class 1 tie being tethered by a frenum reaching all the way to the tip of the tongue, and a class 4 being considered a posterior tie.

Impacts of ankyloglossia

When a breastfeeding mother has a baby whose tongue is restricted, it can become extremely painful to nurse the infant. The baby can also have difficulty removing enough milk from the mother's breast to sustain growth. This issue of poor milk transfer can result in a myriad of breastfeeding problems, including low milk supply, premature weaning, failure to thrive diagnoses, sleep deprivation, psychological impacts of depression and poor bonding between mother and child, gagging, choking or vomiting foods, speech development delays and more (Fernando, n.d.).

The frequency of ankyloglossia reported in our current medical literature encompasses a wide range; and anywhere from 0.02% to 10.7% of babies are reported to have it (Power & Murphy, 2015). Perhaps this range is so wide because of the lack of standardized diagnostic criteria for ankyloglossia. According to the literature, 50% of those considered to have ankyloglossia will not have any difficulty with breastfeeding (Power & Murphy, 2014, p. 490). It does not take much critical thought to question the validity of a statement such as this; indeed, some believe that ankyloglossia is not present unless there are restrictions that would impede breastfeeding (Hazelbaker, 1993) while others include additional challenges beyond breastfeeding within their diagnostic criteria (Kotlow, 2011). The literature is clear that there are many issues impacted by ankyloglossia, even if breastfeeding goes well for the dyad.

An important area of concern related to ankyloglossia is the greater health risks (and their treatment) associated with the inability to correctly utilize the tongue for all its various functions. Sleep apnea is a well-accepted risk of a short lingual frenulum due to the tongue's obstruction of the airway. Of course, sleep apnea is now also being associated with the inflammation of tonsils and adenoids in these children (Huang, Quo, Berkowski & Guilleminault, 2015; Guilleminault, Huseni, & Lo, 2016), and perhaps the unnecessary removal of these organs from the body. These are not useless organs; in fact, tonsils and adenoids are important parts of the body's immune system, acting as a first line of defense against bacteria and viruses entering the body's sensitive mucous membranes (American Academy of Otolaryngology- Head and Neck Surgery, 2018).

Sleep apnea can even put our children at an increased risk for systemic hypertension and poor gut microbiota (Durgan et al., 2016). This poor gut microbiota can

impact a myriad of issues, from behavior, nutritional status and the stress response of the individual involved. The bacteria can even influence the function of entire systems of organs within the bodies and can contribute to many diseases (Sekirov, Russell, Caetano, Antunes & Finlay, 2010). Research is also showing that sleep disordered breathing is associated with a 40% increase for the child having a special educational need (Besson, 2015), including assistance for Attention Deficit Disorder symptoms (Blesch & Breese McCoy, 2016). In fact, up to 95% of those with obstructive sleep apnea experience attentional deficits (Youssef, Ege, Angly, Strauss & Marx 2011). Disordered sleep breathing has already been shown to cause postural deficits like forward head posture (Ozbek, Miyamoto, Lowe & Fleetham, 1998). Since disordered sleep breathing is linked with these deficits, and ankyloglossia is one cause for disordered sleep breathing, Olivi, Signore, Olivi & Genovese (2015) were able to clearly show how frenotomy dramatically improved the posture of study participants and warrants more research on the direct connections which may be found between ankyloglossia and severe spinal structural deficits such as spinal curvatures.

Reflux is another common affliction that is now thought to have a clinical link to ankyloglossia (Kotlow, 2011, Kotlow 2015). There are estimations that up to 25.9% of the US population experiences gastro-esophageal reflux disease (GERD) (El-Serag, Sweet, Winchester, & Dent, 2014). Dr. Scott Siegel (2017) and Dr. Kotlow (2018) have reported that ankyloglossia can cause aerophagia due to the excessive swallowing of air during nursing, and thus causes what appears to be acid reflux in babies. In his research, Dr. Kotlow asserts that infants presenting with reflux are frequently finding complete resolution of symptoms post-revision (2011, 2015, 2018).

Controversy in Treatment

Cho, Kelsberg and Safranek (2010) reviewed the literature and found that a few drops of blood and crying for less than 15 seconds were the only common “complications” found after a frenotomy was performed with scissors. No evidence of research into the rates of complication of laser frenotomies has been conducted, but anecdotally Dr. Larry Kotlow indicates that he has never seen a single case of adverse outcomes related to proper frenotomy technique following his 20,000+ revisions performed (Kotlow, 2018). Cho, Kelsberg and Safranek (2010) indicate that some babies whose tongue ties are mild to moderate in nature can often exclusively breastfeed without intervention; however, any infant with a tongue tie who is experiencing breastfeeding challenges shows immediate improvement following a frenotomy.

There is some debate on private social media sites among parents who believe that a laser frenotomy is always superior to a scissors frenotomy. This debate is present among professionals as well, with the leading world-renowned experts disagreeing. Dr. Hazelbaker encourages scissors frenotomies to release just the visible frenum (not into a diamond shaped-wound) in situations warranted by her diagnostic criteria (Hazelbaker, 2018), and Dr. Kotlow touts the superiority of using the highest available technology (currently a CO2 laser) to perform complete bloodless frenotomies, achieving a diamond shaped wound as indication of the revision’s completeness (Kotlow, 2018).

Physicians' Opinions

A longitudinal study of 71 infants showed that over time, tongue ties do not change in any way (Martinelli, Marchesan, & Berretin-Felix, 2014). This conclusion conflicts with assertions in the literature that untreated tongue ties will stretch or spontaneously resolve during the first year of life (Corrêa, Bonini, & Alves, 2008; Navarro & López, 2002).

It can be quite difficult for a mother to figure out who to turn to if she suspects there might be a tongue-tie. A widely referenced, unique study including 423 Otolaryngologists, 425 pediatricians, 400 speech pathologists and 350 International Board Certified Lactation Consultants (IBCLCs) showed just how controversial ankyloglossia truly is within the professional community (Messner & Lalakea, 2000). Findings revealed that almost 70% of IBCLCs, but a small minority of pediatricians and otolaryngologists believe that ankyloglossia is "frequently associated with breastfeeding problems," which may explain some of the United States' deplorable breastfeeding success rates. This again shows how pediatricians seem to ignore the impact of tongue ties, just 21% of them versus 50% or more of otolaryngologists and speech pathologists believe that ties are only "sometimes associated with speech difficulties." Surgery is recommended "at least sometimes for feeding, speech, and social/mechanical issues" (such as speech impediments or difficulty licking lips/kissing) by percentages from 19-29% by pediatricians, as opposed to 53-69% of otolaryngologists (Messner & Lalakea, 2000 p.125-126).

Not included in the above referenced study are the obstetrics-gynecology (OB/GYN) providers, the final piece of the puzzle for mothers experiencing breastfeeding difficulty. Given the fact that most mothers have at least one or two follow up visits with the provider who attended their birth within the first six weeks postpartum, it would be in her best interest if she had a professional who had received some breastfeeding specific training during their educational experience. So, Freed, Clark, Sorenson, Lohr, Cefalo and Curtis (1995b) set out to survey OB/GYNs and 3,275 of them responded. Surveys included questions regarding their training and education and quizzed them on what to do for certain common breastfeeding challenges. It was discovered that:

“Less than 50% of residents chose appropriate clinical management for a breast-fed jaundiced infant or a breast abscess. Practicing physicians performed slightly better, but still more than 20% chose incorrect advice for mothers with low milk supply... The greatest predictor of physician self-confidence was previous personal or spousal breast-feeding experience (Freed, Clark, Sorenson, Lohr, Cefalo, & Curtis, 1995b p. 1609).”

The fact of the matter is that many care providers are inherently prevented from screening for ankyloglossia since they lack clear and concise industry guidelines from professional groups such as the American Academy of Pediatrics and the American College of Obstetrics and Gynecology- which offer confusing and conflicting information about ankyloglossia (AAP, 2015; AAP, ACOG, 2012). The American Academy of Family Physicians recommends frenotomy in cases of ankyloglossia, however does not provide guidance for screening tools or how a frenotomy should be performed (AAFP, 2010). One major resource that is not mentioned by any of these industry organizations is

the Academy for Breastfeeding Medicine, which not only provides the Hazelbaker Assessment Tool for Lingual Frenulum Function (HATLFF) diagnostic tool but also explains it and goes so far as to clearly explain the process of performing a frenotomy with scissors (Academy of Breastfeeding Medicine, 2004). Without a cohesive agreement on diagnostic criteria, it is unlikely that there will be any foreseeable future where babies can be universally screened and treated for ankyloglossia.

Maternal Perspective

Breastfeeding can be an integral component to the maternal experience for many women. Maternal identity changes and evolves with the birth of each child. The concept of maternal identity is defined by Riordan and Wambach (2010) as “establishing intimate knowledge of the infant and feeling competent and confident in mothering activities, [and] feeling love for the infant” (Riordan & Wambach 2010, p.740). Maternal Role Attainment Theory indicates that the process of having a baby does not simply turn one into a mother, but that a series of events over the first four months after the baby is born which contribute or detract from her self-confidence as a mother play a role in this process and can profoundly impact the bond between a mother and her child (Husmillo, 2013). This helps to explain why there is no faster way to ensure a mother feels incompetent as a mother than to tell her either that there is nothing wrong with her baby when she has painful, bleeding nipples, or that there is simply nothing that can be done to improve the situation (Riordan & Wambach, 2010).

It seems that the most common emotion women encounter when they are experiencing difficulty breastfeeding tongue-tied babies is an extreme level of frustration.

Women interviewed in a phenomenological study done in Australia reported that they experienced health practitioners who seemed ignorant to the plight of nursing mothers with tongue-tied babies and who were not able to offer any useful insight or advice concerning their breastfeeding challenges (Edmunds, Fulbrook & Miles, 2014). They reported that everyone they spoke to about their difficulties feeding had different advice for them. Of those in this study whose babies received frenotomies, every single woman interviewed reported their breastfeeding experiences improved dramatically. The remaining three whose babies did not receive frenotomies reported some improvements but experienced ongoing difficulties. One of the strongest statements in this study included the common-sense fact that: “Breastfeeding difficulties should not be seen as a normal process, especially for women whose infants have tongue-tie” (Edmunds et al., 2014, P.194).

Difficulties finding Treatment

The risks that come from not breastfeeding our children are more well-known now than at any point in history. Increased risks of pneumonia, diarrhea, obesity, diabetes, cancer, Sudden Infant Death Syndrome (SIDS) and other illnesses leading to death are associated with formula-feeding infants (Stuebe, 2009). For mothers, breast and ovarian cancers, diabetes, weight gain and metabolic syndrome are more prevalent among women who did not breastfeed their children (Stuebe, 2009). Long-term protections of breast milk have been discovered, including less inflammatory diseases and lower blood pressure and cholesterol in those breastfed as infants (Schack-Nielsen & Michaelsen, 2006).

This data leads one to question how so many birth providers, who are the mother's primary caregiver during her immediate postpartum period and therefore are likely to be questioned regarding any difficulties she may be having with breastfeeding, are responding to these questions when they have received so little evidence-based training. A logical assumption would be that they are leading families based on anecdotal evidence from personal experience, which may or may not be helpful or applicable to her individual situation; however there seems to be no alternative offered to this since the education is simply not required of them in order to obtain their credentials. The Freed, et al. (1995b) survey of practicing OB/GYNs showed not only that the bulk of their breastfeeding instruction occurred in lectures or hospital rounds--neither of which have been shown to be active forms of learning--but also that common misconceptions were not changing from the first year of residency to the last, which indicates that little to no breastfeeding education was happening during this vital time.

Perhaps more concerning is that just 61% of all the residents agreed that breastfeeding is the optimal form of nutrition during the first several months of a baby's life. Perhaps even worse is that only 57% of active OB/GYN Practitioners agreed that breastfeeding was the optimal source of nutrition for newborns. If that was not startling enough given current breastfeeding recommendations, only very few residents (37-38%) and less than half (48%) of practitioners were aware that supplementing with formula during those first crucial weeks of life is one cause of breastfeeding failure (Freed *et.al*, 1995b). It is no wonder that our national breastfeeding success rates are abysmal in comparison with the number of women who start off breastfeeding at birth (CDC, 2014).

Social Impacts

Sleep apnea, systemic hypertension and poor gut microbiota caused by tongue-ties can impact many social factors within one's life. It is further complicated by poor gut microbiota impacting even our very responses to stress, thereby bringing with it the potential of worsening the emotional impact of all these issues upon the individual.

Attention deficits can impact social function, as can chronic fatigue due to the disordered breathing and obvious subsequent impact on emotional control, which is clearly already a challenge for young children in the best of circumstances. Complicate that further with a dramatic increase in the need for special education services (Dollberg, Manor, Makai & Botzer, 2011; Messner & Lalakea, 2002), add in speech and language challenges (Ito, Shimizu, Nakamura & Takatama, 2015) Ostapiuk, 2006; Walls, Pierce, Wang, Steehler, Steehler & Harley, 2014; and there is a child who is ripe for bullying within the current culture of schools within the U.S.A. at the time of this writing.

Breastfeeding and postpartum depression

If tongue-ties frequently interfere with breastfeeding, then it can be seen how the lack of standardized diagnostic and treatment criteria is likely to result in preventable failed breastfeeding experiences. A much under-discussed (but not under-researched) topic of interest is the relationship of breastfeeding success and postpartum mental health. The idea that breastfeeding success and confidence is associated with a lower risk of Postpartum Depression (PPD) is not considered to be controversial in nature. In fact, a successful breastfeeding relationship has been shown to have a clear cause and effect association with PPD (Sá Vieira, Torquato, Moraes Di, Maite, & Aparecida, 2016; Wedad Saad, Buthainah Ali, Bushra Ahmed, Abdullah & Nourah 2018), especially in

women of low socioeconomic status (Catarine, Marilia, Leopoldina, Juliana, Jailma, Niedja & ... Pedro, 2017). Many parents of newborns understandably struggle to get enough sleep; however, one can easily see how mothers of newborns who are struggling with breastfeeding might experience an increased level of sleep deprivation. Research does indicate that mothers with PPD (who are likely to also be experiencing difficulties with breastfeeding) who do not get enough sleep are at a greater risk for more severe depression (Stone, 2013). On the other side of this coin, studies also indicate that breastfeeding can, in fact, decrease active PPD symptoms and that breastfeeding mothers have an overall lower rate of PPD (Ashraf, Azadeh Zamani, & Reza Davasaz, 2012).

Breastfeeding Success, Postpartum Mood Disorders, and Child Maltreatment

Families whose mothers have clinically significant depression (i.e. that it indisputably impairs their ability to function) and those with clinically significant post-traumatic stress disorder (perhaps due to a traumatic birth experience) were found to be at a higher risk of experiencing child maltreatment than control groups (Muzik, Morelen, Hruschak, Rosenblum, Bocknek, & Beeghly, 2017). Breastfeeding success gained through tongue-tie treatment can decrease the risk and/or severity of postpartum mood disorders, so therefore could have a positive impact in reducing the risk of child maltreatment. Treatment for and prevention of these postpartum mood disorders may help mitigate their impact on the maternal experience and the children of these parents (Choi, & Sikkema, 2016).

Structural Abnormalities Associated with Ankyloglossia

There seems to be general agreement among those studying orofacial myofunctional disorders that ankyloglossia causes disorders in the growth and function of the face and oral cavity, by impairing their development. Evidence is clear that the more severe the ankyloglossia (according to Dr. Kotlow's criteria), the more severely atypical the dental arches and overbite between upper and lower teeth (Srinivasan & Chitharanjan, 2013); specifically, a narrow arch and high palate (Yoon, Zaghi, Ha, Law, Guilleminault, & Liu 2017). This impaired development can be a major contributing factor to the restriction of the upper airway (and therefore sleep disorders), postural alterations (due to the tongue, facial and bone structures of the head and torso's interconnectedness) and it has been shown that delay in addressing the root cause of the disordered growth may eventually lead to the need for orthodontic treatment in the future and even the need for surgical realignment of the jaws down the road (Fabbie, 2015).

Integrative Healthcare

There is more research coming out in recent years in support of the addition of complementary therapies before or after treatment for ankyloglossia. The current evidence is in favor of integrating a variety of approaches, such as myofunctional therapy to reduce scar retraction (Ferrés-Amat, Pastor-Vera, Rodriguez-Alessi, Ferrés-Amat, Mareque-Bueno & Ferrés-Padró, 2017). This means that myofunctional treatment may help reduce the risk of scar tissue forming in place of the revised frenulum and creating a similar restriction, as the scar tissue can retract and pull the tongue downward, tethering it once more. Evidence is also supportive of chiropractic (Miller, Miller, Sulesund &

Yevtushenko, 2009), craniosacral (Berg-Drazin, 2016) and osteopathic (Herzhaft-Le Roy, Xhignesse & Gaboury, 2016) therapies to support adequate suck function and breastfeeding behaviors in nursing babies.

Of course, the current state of healthcare availability due to health insurance issues within the United States greatly limits the availability of these services to families. As most insurance will not cover many of these treatments, they are essentially unavailable for those who cannot afford out-of-pocket treatments.

Conclusion

The currently available literature paints a bleak picture for the breastfeeding relationship between a mother and tongue-tied infant. Beyond the myriad health and behavioral issues related to ankyloglossia, it can be quite difficult for a mother to figure out who to turn to if she suspects one might be present. Research clearly shows that ankyloglossia has been uniquely devastating to the breastfeeding dyad throughout the last century of motherhood, and it continues to devastate the breastfeeding relationships of today as well as set a child up for health and social risks as they grow considering its controversial nature among professionals. Unless lactation and pediatric medical professionals, whose responsibility it is to care for society at large as well as the breastfeeding dyad, can agree upon and universally screen for ankyloglossia, there are likely to be innumerable more failed breastfeeding relationships.

It is clear that while there is a great deal of controversy among medical professionals regarding breastfeeding with ankyloglossia (whether ankyloglossia is present, and whether it should be treated at all), the controversies are largely incongruous

with the plethora of peer-reviewed data in existence today. With the knowledge that tongue-ties do not change over time (Martinelli, et.al, 2014), that complications from frenotomy are extremely mild- a few drops of blood and less than 15 seconds of crying, on average (Cho et al., 2010), that frenotomy helps an overwhelming majority of mothers breastfeed without incident (Edmunds, et.al 2013), and that it impacts so many facets of one's overall health and physiology, it seems obvious that this low-risk and extremely effective procedure should be performed. The challenge for the mother, then, is to find a medical professional who has received adequate training on the subject matter to diagnose and treat the tongue tie. Though the data shows that while her International Board Certified Lactation Consultant (IBCLC) will likely find it, her IBCLC is legally unable to perform the procedure in most countries and has to refer to another provider – however, this provider, whether it is an Otolaryngologist, Pediatrician (Freed, et.al, 1995a) or OB/GYN is likely to have had very little training on breastfeeding in general, let alone something as specific as ankyloglossia (Freed, et.al, 1995b). Holistic practitioners can support the dyad through ankyloglossia treatment and habilitation, however there is no data indicating that complementary therapies alone can adequately treat ankyloglossia. While these therapies have been shown to improve breastfeeding and function in tandem with frenotomies, they are essentially unattainable for families who cannot afford to pay for each treatment out of pocket, as they are seldom covered by health insurance.

Chapter 3: Methodology

Diagnostic Criteria Project

Two research projects were undertaken for this thesis. First, a Diagnostic Criteria project was intended to ascertain whether the chosen diagnostic tool would impact the frequency of positive breastfeeding outcomes, or whether any consistent diagnostic screening was a factor that would impact breastfeeding outcomes.

Quasi-Experimental Approach

While randomized controlled trials represent the gold standard of clinical efficacy, there are many circumstances in which that methodology is not possible or ethical (Bärnighausen, Røttingen, Rockers, Shemilt, & Tugwell, 2017). In these cases, a quasi-experimental approach offers the opportunity for causal inferences to be made about healthcare issues. The main difference between a true experimental design and a quasi-experimental design is that in quasi-experiments, there is no random assignment. This allows for the researcher to look at the variables and their relation to outcomes without the ethical concerns of withholding treatment or key health screenings for study participants. In this study, that means that all babies will be assessed for ankyloglossia to ensure that all babies who participate will be receiving the highest level of evidence-based care.

Some benefits of quasi-experimental approaches are that they can account for control with regard to size estimations, leave natural contexts undisturbed, and avoid any threats to validity or artificiality that is a common trouble with trials of research. Due to

the fact that healthcare researchers cannot create true control groups among humans, it is virtually impossible to conduct a true experimental process with human subjects. By using larger sample sizes, quasi-experimental studies can circumvent the need for strict control groups by studying the causal effects of various approaches on a particular demographic, as a large enough group will make up for the lack of control with regard to the experiment's validity and reliability (Bärnighausen, et al., 2017).

Cohort Studies

A cohort is a well-defined group of participants who are observed over time for outcome(s) of interest to the study. The cohort can be either closed (enrollment dates are firm, no exit allowed), or open (participants are able to move in and out dynamically) (University of Florida, 2013). A prospective cohort study collects data on all study participants before any of them have developed outcomes of interest to the study. All subjects are then followed through a period of time to see what happens, either through in-person interviews, questionnaires, phone interviews, medical testing, etc. Data analysis cannot be completed until a sufficient amount of time has passed and enough "outcomes" have occurred. Once those outcomes have occurred, participants are generally followed longitudinally so the researcher can track outcome results over time (Boston University, n.d.). For this research study, the prospective cohort sample will include babies born to three different birth providers during a three-month period, covering the range of birthing experiences- home birth, hospital birth, and birth center births.

By having multiple birth providers perform tongue tie assessments on babies born, the best data can be obtained with as little interference of potential variables as possible. All providers were followed for a period of three months, and all had access to

ask questions at any time they saw fit in order to ensure understanding and trouble shoot any issues.

With any scholarly research study, there will be risk of bias. Assessing risks of bias is core to obtaining high-quality data, which is an important component of the quasi-experimental approach in particular because of what are dubbed *unobservables*. These components include variability in instruments used, time duration and interruption within the study, natural experiments and more (Waddington et al., 2017).

Research Methods, Diagnostic Criteria Project

A quasi-experimental approach was utilized in this research, as reported by a cohort of birth providers working in a variety of birthing locations; private homes, birth centers, and hospitals. To minimize the risk of bias, a variety of qualifications and credentials was sought out in research participants. Participants include an OB/GYN and three Certified Nurse Midwives (CNMs) working in a variety of locations: a freestanding birth center, home births, and hospital births. One of the CNMs is also an IBCLC, and another of the CNMs provides scissors frenotomies to babies born in her practice.

During the three-month period of data collection for this research study, a cohort of 25 babies were screened for ankyloglossia as part of their newborn assessments by their birth providers and assessed for variables related to breastfeeding success and tongue tie revision (when indicated by clinical assessment). Each baby was assessed using one of the two available diagnostic tools; the Hazelbaker Assessment Tool for Lingual frenulum Function (HATLFF) and Dr. Larry Kotlow's TOTs classification criteria. Relatively few unbiased research studies have been conducted on the various

diagnostic tools, so the two chosen here were selected because they are the most frequently discussed in scholarly literature.

Those babies found to have ankyloglossia were tracked and their breastfeeding success compared to those who were not found to have ankyloglossia. The level of agreement between the two scales will be noted, as was breastfeeding success of those babies that did not receive the same diagnosis between both scales. Breastfeeding success was considered to be exclusive breastfeeding without supplementation in accordance with the mothers' original breastfeeding intentions (exclusive breastfeeding, mixed-method feeding of breastmilk from the breast and from a bottle, mixed-method feeding of breastmilk and intentional formula use, or the supplementation of additional breastmilk or formula by bottle because of weight-gain or milk-transfer concerns with the baby).

Though there is a plethora of data in existence proving the existence of ankyloglossia and its impact on the breastfeeding dyad, it is still challenging in many areas of the U.S. for parents to locate a provider that has been trained to identify and/or revise it. This is an example of an unobservable variable, as the training and skill level of the provider sought by the breastfeeding parents to provide frenotomies in the event of an ankyloglossia diagnosis is going to be a major unknown factor. As there is no industry standard (or even a standard professional performing frenotomies), it would be impossible to include this data at this point in time in such a way that would contribute to the reliability of safe and effective procedures.

Survey Project

A survey project was completed next to learn whether providers were routinely being trained in tongue-tie, from whom they received their instruction, how effective their training was with regard to teaching them evidence-based information about ties and the ways in which their education impacted their daily practice.

Mixed-Method Survey Approach

The internet is so widely used among Americans that it is lucrative to collect data with internet-based surveys. The speed of data collection, large number of potential respondents and the low associated costs of surveying people online makes this method of collecting data preferable to others. The requirement of responses to all questions is cautioned against, as it increases the likelihood of respondents either answering erroneously in order to move on or abandoning the survey altogether. (Dillman, Smyth & Christian, 2014).

Convenience Sampling

A truly randomized sample of individuals is difficult to gather using social media sites, as so many like-minded individuals tend to find themselves lumped together in discussion groups online. For the purpose of this study, Facebook is utilized for the sake of having access to a larger number of professionals in a time and cost-effective manner. This may also be considered a limitation, as survey respondents are likely to have a special personal or professional interest in the subject area in which they are being surveyed. Another limitation is that potential respondents are regular social media users, and it is known that social media is not universally used among all people.

Research Methods, Survey Project

Data were collected via an online survey that was available via Survey Monkey. The survey questions were primarily quantitative but included some open-ended questions for qualitative data collection of further elaboration or explanation of answers. Questions were asked regarding demographics, time spent in practice, training/credentials received and an assessment for ankyloglossia knowledge and level of integration of training received in ankyloglossia into their practice.

A convenience sample of professionals was obtained by email and Facebook group posts. To be included, participants needed to have the ability to read and write English, have access to the internet, and routinely assess infants as part of their profession. This research was conducted with approval from Union Institute and University's Institutional Review Board.

Some limitations of a survey such as this involve the fact that respondents are limited to those present in Facebook groups of professionals, which may not be representative of industry professionals as a whole. However as of 2017, an estimated 72.4% of the U.S. population currently uses Facebook (Miniwatts Marketing Group), so it is reasonable to assume a fairly wide cross section of individuals may be present in these groups. It is a distinct possibility that those with a particular professional interest in tongue-tie would be interested in participating in a survey such as this, so there is a risk that respondents are biased in favor of diagnosing and treating individuals with tethered oral tissues.

Theoretical Approach

The theoretical research foundation utilized to interpret data and influence the recommendations of this thesis is the Social Constructivist Theory. The theory purports that social constructivism explains the evolution of practices within a professional industry by incorporating newfound information and knowledge, helping to make sense of existing practices in their original context, and how the incorporation of that new information alters industry practices over time (Thomas, Menon, Boruff, Rodriguez & Ahmed, 2014). This is, in essence, the evolution of evidence-based practices, and is useful to explore why these industries should be providing evidence-based care to families struggling with the myriad issues related to tongue ties, especially in newborn babies. Social Constructivist Theory is the chosen paradigm within which to view this research because the importance of early diagnosis and treatment of ankyloglossia has been clearly shown to improve breastfeeding outcomes as discussed in Chapter 2. It is widely accepted among professionals that breastfeeding success benefits both mother and child, that the current breastfeeding success rates in the United States are deplorably low, and that ankyloglossia impacts at least 2-5% of the population. The literature shows very clearly that ankyloglossia negatively impacts the breastfeeding dyad and that frenotomy is a relatively quick and easy procedure with virtually no risks when performed in a sterile environment by trained professionals. As such, social constructivist theory can make it clear that it is a travesty that so few industry organizations recommend the screening and treatment of ankyloglossia. The importance of universal screening for ankyloglossia during all newborn assessments to breastfeeding success outcomes, and ultimately, to public health is very clear when viewed through this lens.

Chapter 4: Results

The Diagnostic Criteria project aimed to ascertain whether using the HATLFF diagnostic form or the Kotlow diagnostic criteria would have a more successful impact upon the breastfeeding relationship in the event of tongue-tie. Since all participants assessing infants had the benefit of a clear and consistent explanation of each set of diagnostic criteria (Appendices A and B) and the ability to ask follow-up questions to ensure clarity and understanding, it can be surmised that they obtained even more education and assistance than would be typically available for a medical professional working with newborns. However, each provider collecting data did so in a slightly different way and still appeared to have had different ideas of to whom to refer babies who did have ankyloglossia for revisions, which babies had (or didn't) have ankyloglossia and what treatment should be recommended. Due to this variable (the provider referred to for the tongue-tie revision) being unaccounted for, data were found to be irrelevant, as it was discovered that different revision providers adhered to differing methods of revision and post-revision protocol- so not only were providers assessing infants differently despite using the same diagnostic criteria, but providers were referring infants found to be tied to revision providers who practice differing methods of revision.

Based upon conversations with the participants, it appears that the lack of standardized training available in better utilizing these tools in a diagnostic practice has had a larger impact on the ability to collect good data than originally anticipated. The individualized training offered still failed to provide them with the confidence and competence needed to assess for ankyloglossia in a consistent manner.

As a result of these findings, a secondary research project was conducted via survey to ascertain the level of education received by providers who work with infants and young children in a capacity where assessing for TOTs would be considered to be within their scope (i.e. IBCLCs, OB/GYNs, Midwives, Dentists, ENTs, etc.). The goal of the Survey Research Project was to ascertain whether there was any correlation between a provider's personal experience with TOTs and their decision to seek specialized instruction/training on their diagnostics and treatment. A secondary goal was to gauge the level of awareness providers have with current, evidence-based information on TOTs.

The survey was distributed via email to providers in the Western NY area, where it was requested that they disseminate among their contacts, and in private lactation, midwifery, airway-specific and dental professional groups on Facebook. All respondents were asked to disseminate to their various professional contacts. The survey yielded 135 responses from a variety of providers. Dentists, speech and language pathologists, pediatricians, oral myofunctional therapists, dental hygienists, ear nose and throat (ENT) doctors, midwives, chiropractors, craniosacral therapists, registered nurses, physician assistants and lactation support providers responded. Many providers also carried lactation support credentials, but 54% of respondents carried some level of lactation credential.

Six questions were analyzed for inter-reliability (Table 1). A mildly significant negative correlation was found between Q10 (Have you ever received formal training or lectures on the subject of ankyloglossia?) and Q14 (Did you incorporate the use of this diagnostic tool into your practice?), ($r=-.489$, $p<.001$), and Q14 and Q13 (Did your formal tongue-tie training or lecture include instruction on the utilization of a diagnostic

tool for your use to assess for ankyloglossia?) had a strong positive correlation ($r=.593$, $p<.001$).

Table 1:

Correlations Table

	Q1	Q7	Q9	Q10	Q13	Q14
Q1	1.0					
Q7	-.109	1.0				
Q9	.052	.077	1.0			
Q10	-.279*	-.048	-.078	1.0		
Q13	.218	.134	.007	-.476	1.0	
Q14	.270*	-.159	.059	-.489**	.593**	1.0

Notes: N=42; $p<.05^*$; $p<.001^{**}$

A predictive analysis was run (Table 2) to determine what factors, if any, would predict the type of practitioner likely to obtain training on oral tethers. The full model that includes the type of practitioner as the dependent variable and Q7, Q9, Q10, Q13, and Q14 predictors accounts for 11.4% of the variance in type of practitioner [$R^2=.114$, $F(5, 36)=.926$, $p=.475$, 95%] (Table 2). Not only did the model lack significance, but none of the predictors significantly contribute to this model when controlling for all other predictors.

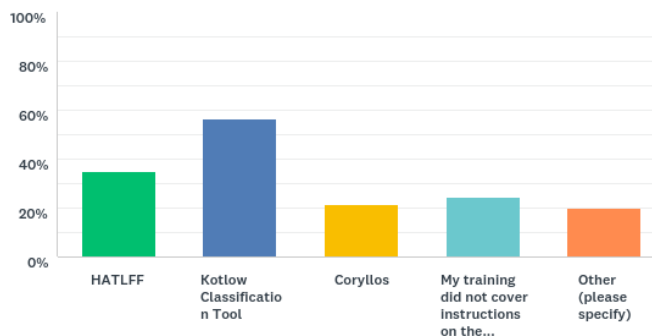
Table 2:

Multiple Regression Results and Significance Testing

	<u>Full Model</u>
N	42
R ²	.114
F	(5,36) .926
β	
Q7	-2.168
Q9	.256
Q10	-3.277
Q13	.150
Q14	1.551

However, the rest of the survey showed some startling evidence. Figure 1 shows that of those who received instruction on a diagnostic tool during their formal training or lecture, more than half (56.38%, or 53/94) learned Kotlow's tool, 35.11% (33/94) learned HATLFF, 21.28% (20/94) learned Coryllos and a whopping 24.47% (23/94) did not cover diagnostic tools at all. The remaining 20% included a variety of lesser known and less researched tools. Figure 1: Question 13 Responses

Q13 Did your formal tongue-tie training or lecture include instruction on the utilization of a diagnostic tool for your use to assess for ankyloglossia? Check all that apply.



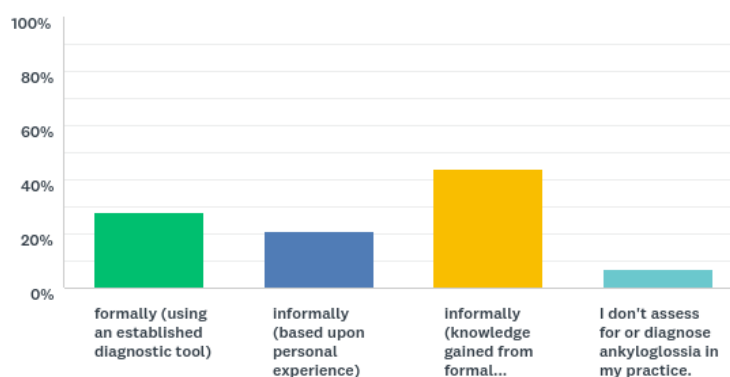
Of those who have received formal instruction on ties through professional lecture or training, 44% of respondents choose not to use a diagnostic tool to assess for tongue-

tie, with only 27.91% reporting that they use any diagnostic tool at all in their practices.

Figure 2: Question 9 Responses

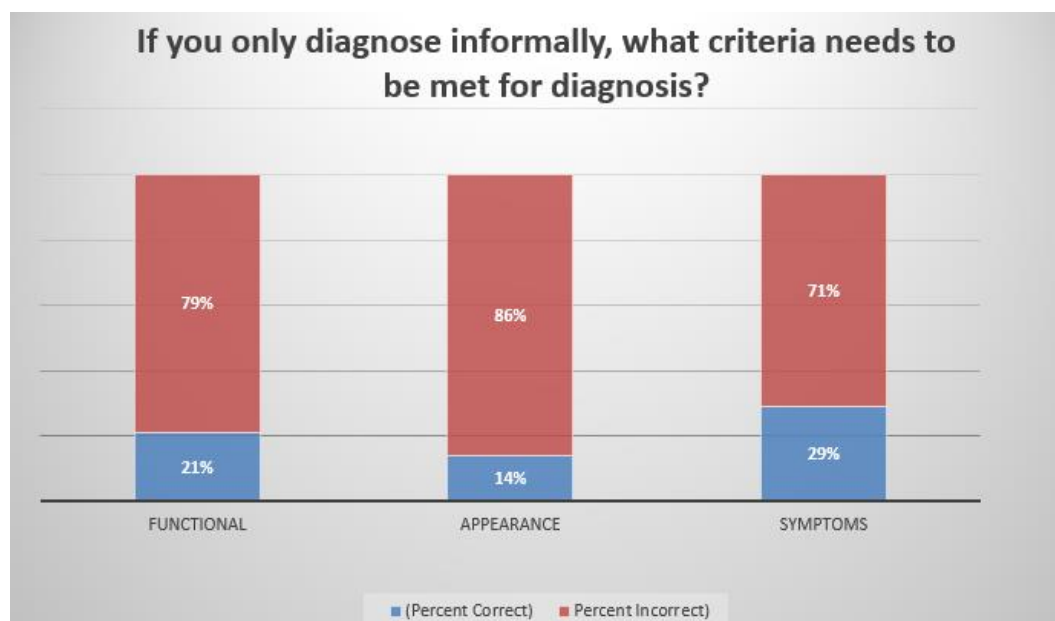
Nearly 21% of respondents report that they assess for tongue-tie without using any tool and without receiving any formal training on the subject (Figure 2).

Q9 Do you assess for or diagnose ankyloglossia in your practice?



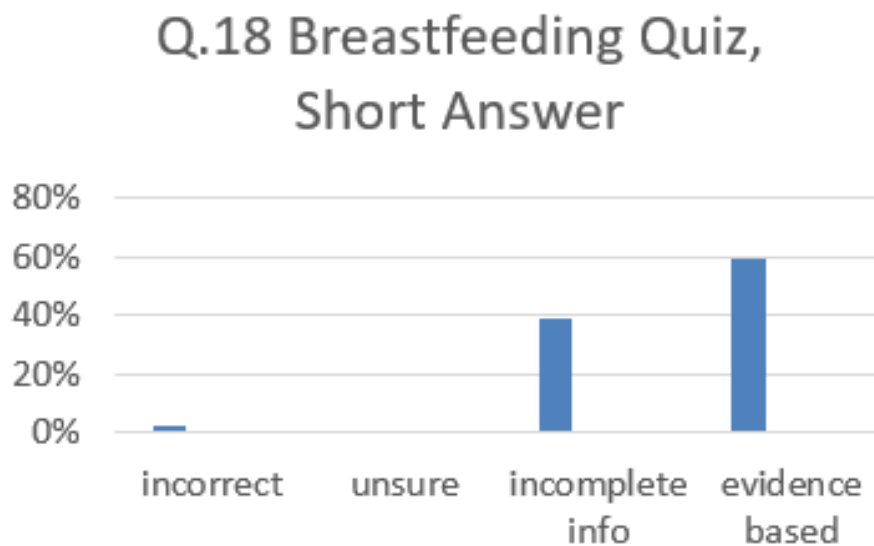
When those who assess for ties without having had any formal diagnostic tool or having attended lectures on TOTs were requested to list the criteria they use in three areas; functional, appearance, and symptoms, a small minority of respondents provided evidence-based responses- 21%, 14% and 29%, respectively (Figure 3).

Figure 3: Question 17 Responses



Of the formally educated providers, their knowledge of evidence-based research was assessed over 5 broad areas- breastfeeding, airway, reflux, posture, and autoimmune. It was no surprise that the majority of respondents gave a correct answer with regard to breastfeeding impacts, as 54% them are lactation support professionals. However even taking this under consideration, as noted in Figure 4 just 59% of them provided evidence-based responses to the question requesting an explanation of how tongue-tie can impact the breastfeeding experience. Thirty-nine percent provided correct, but incomplete information.

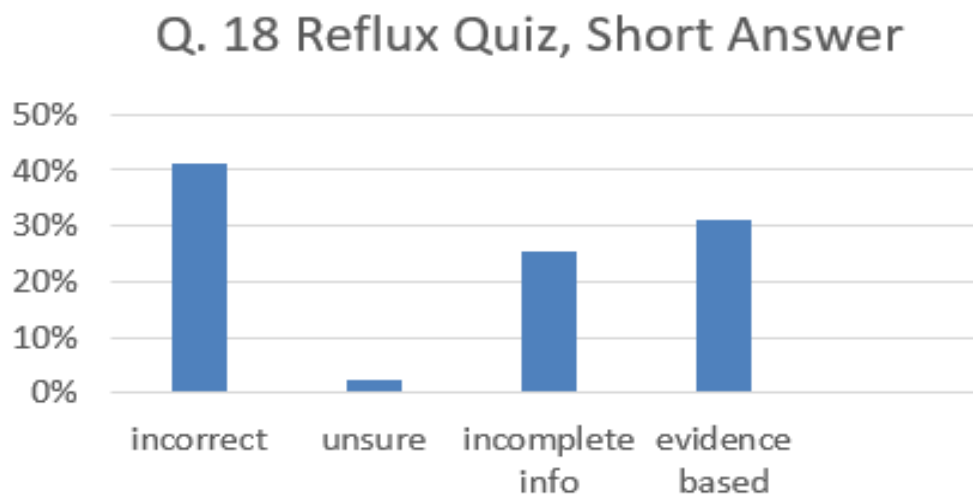
Figure 4: Breastfeeding-Specific Responses to question 18: What are the physiological symptoms related to the following areas that you are aware of in regard to tongue-tie? If none, write "none."



The concerns, however, crop up when one learns that 34% provided incorrect answers when asked to explain the impacts of TOTs on the airway, with just 19% providing evidence-based information. 42% provided correct but incomplete information, and just 4% answered that they were unsure of the impacts upon airway.

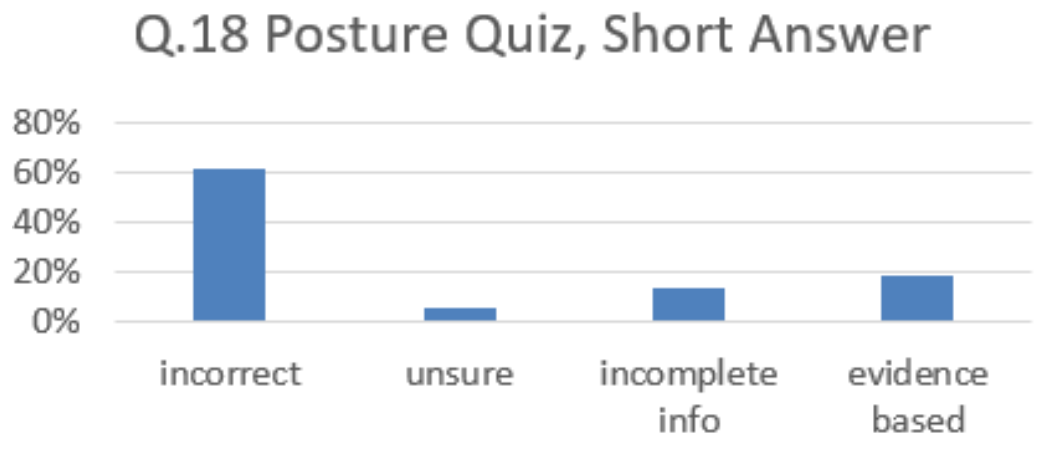
When asked to explain the links between TOTs and reflux, figure 5 shows that the level of information not based in current evidence skyrocketed to 41%, with just 31% citing information based in evidence, as explained in the review of the literature contained earlier in this Thesis. A full 26% of respondents were in the right ball park with the information they gave, but it was incomplete. Again, just 2% acknowledged that they did not know of any link between TOTs and reflux.

Figure 5: Reflux specific responses to question 18: What are the physiological symptoms related to the following areas that you are aware of in regard to tongue-tie? If none, write "none."



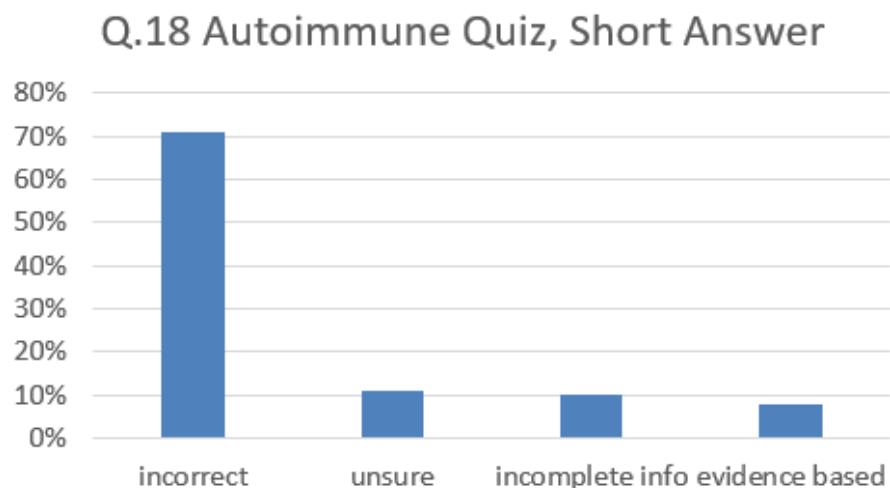
When asked about the impacts TOTs may have on the posture of an individual, Figure 6 shows the number of incorrect/non-evidence-based information jumped to 61%, with just 6% admitting that they didn't know. In this category, just 19% provided evidence-based information, and 13% gave correct but incomplete info.

Figure 6: Posture specific responses for Q 18: What are the physiological symptoms related to the following areas that you are aware of in regard to tongue-tie? If none, write "none."



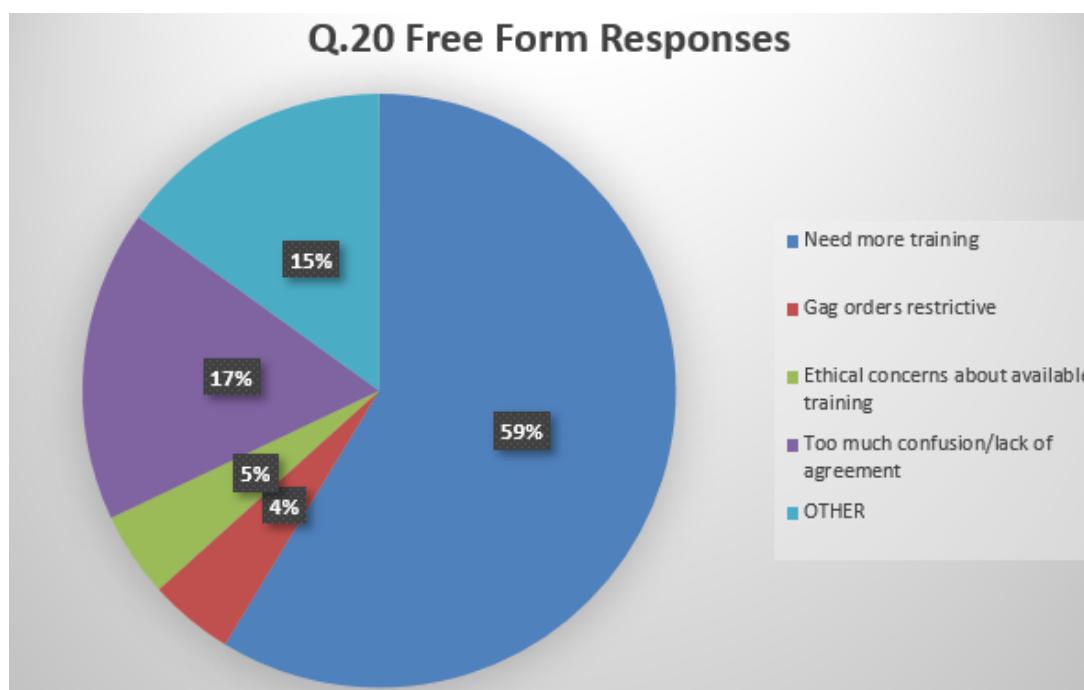
Finally, on autoimmune impacts related to ankyloglossia, a large majority of respondents answered incorrectly- 71%, while 11% admitted they did not know of any link between TOTs and autoimmune dysfunction. Just 8% provided evidence-based responses, with 10% more providing correct but incomplete answers (Figure 7).

Figure 7: Autoimmune specific responses for Q 18: What are the physiological symptoms related to the following areas that you are aware of in regard to tongue-tie? If none, write "none."



When offered the opportunity to offer any other thoughts they had on the matter of TOTs, 58% of providers said they wish that they had access to more training on TOTs. 17% stated there was too much confusion as a result of lack of agreement between professionals in varying healthcare fields and stated this was a major inhibitor for them in ascertaining which data was reliable and which was not. Also of note were ethical concerns about training available- that those providing training may be in it for the money they would receive in referrals, and yet others expressed frustrations with gag orders from their place of employment (hospitals or pediatric offices) which restrict them from discussing TOTs at all with their patients.

Figure 8: Question 20: Is there anything more you wish to tell us regarding the availability (or lack thereof) to learn about or quality of training related to tongue-ties, and how this relates to your professional practice?



Chapter 5: Discussion

Discussion of the Results

The original intention of this research was to discover whether the diagnostic tool used to screen for ankyloglossia is as important as whether any tool is being used at all, and whether the lack of standardized training on either of these tools impacts their efficacy in practice. It began as a Hazelbaker versus Kotlow exploration, to see whether one of their diagnostic tools yielded better results for breastfeeding mothers, and presumably, was inherently “better” than the other with one focusing on the function necessary to succeed with breastfeeding and the other more generalized and with far less specificity.

As it turned out, the wrong questions were being asked. The results of the Diagnostic Criteria Study made it clear that the question was not which tool was being used. It called into question the level of education and awareness of current evidence on which providers base their practice, for whom it is within their scope of practice, to assess, diagnose, and/or revise ankyloglossia.

When reviewing the results of the Survey Project, it was expected that a strong relationship would be found between questions 10, 13, and 14 (Table 1), which is that providers received training on ties, that the training included information on diagnostic tools and that they incorporated those tools into their respective practices.

Figure 1 showed that the majority of providers choose not to use any evidence-based screening tool for tongue-ties, with just under 30% of respondents using anything

at all. Since the majority (about 75%) of those who did receive training also learned about specific diagnostic tools, one wonders why providers choose not to use their education.

Perhaps the most concerning is that almost 20% of providers (Figure 2) surveyed reported that they do assess for tongue tie, except less than a third of those providers were able to provide any evidence-based diagnostic criteria. How can a provider provide evidence-based care for their patients when they are deliberately refusing to obtain the necessary evidence?

Figures 3-7 reviewed the short answer quiz offered to those who did receive formal training on tongue-ties. To their credit, with 54% of survey participants having lactation support credentials, breastfeeding was the area in which the majority of responses were evidence-based, though the correct answer rate was still just 59% with another 39% providing correct, but incomplete information. The other areas quizzed sought to ascertain what the level of evidence providers were familiar with, with regard to how tongue-tie impacts the airway, reflux, posture and immune function. The results in these areas were nothing short of abysmal, with the largest rate of evidence-based responses at just 31% and extremely few (11% at most) acknowledging that they were unaware of any link. More often than not, respondents erroneously claimed that there was no evidence to support a link between TOTs and each respective area. The humility that accompanies an acknowledgement of there being more to learn seems to be a rare trait among the majority of professionals within the field.

The free form responses (Figure 8) provided a never-before studied perspective that does provide some hope in the face of so many providers claiming that evidence simply does not exist when really, they were just unaware of its existence. More than half

of respondents (59%) indicated that they wished there were more training on TOTs available, with another 17% complaining about the controversies within the field making it difficult to know which training is trustworthy and based in the latest evidence.

Importance of the Findings

The incongruence among medical professionals, an inquiry of the training they have received, tools they use and information they have generalized from that training and incorporated into their practices on the subject of ankyloglossia has not previously been explored in the literature. It does appear that lactation support professionals tend to be more aware of evidence-based information, however with such a low percentage of overall breastfeeding success within the United States, it seems that very large numbers of individuals with tethered oral tissues are unlikely to be assessed by any lactation support professional, let alone one who may have received special instruction in this area.

Social constructivism has us view this data as a call for action for medical providers who are not adequately educated on TOTs. Clearly those who are relying on those providers to address these issues competently are being let down in startling numbers. This lack of evidence-based practice hits underprivileged families especially hard, as they are frequently without access to affordable supports to manage each related symptom of a tongue tie- many of which are not covered at all by medical insurance. The rates of postpartum mental health issues, disordered sleep breathing, behavioral and educational deficits are well-known to be higher among impoverished communities within the United States. If providers care to advocate for their patients, then they are duty-bound to stay up-to-date on current research from both within and outside of their

respective fields of practice. The only way to elevate the healthcare industry is to incorporate new evidence and knowledge into daily practice.

Ethical Implications

If providers are unsure of how and when to screen for ankyloglossia and they do not agree upon or know how to perform a revision of ankyloglossia that routinely alleviates all related symptoms, then it follows that families of children with ankyloglossia are missing out on the opportunity to make informed choices regarding the care of their children, their feeding methods (i.e. breast or bottle feeding), and even potentially special needs placement in school should their child have behavioral or developmental deficits resulting from disordered sleep breathing related to tongue-tie.

Doctors Hazelbaker and Kotlow have clearly done a tremendous job teaching healthcare providers about tongue-tie and their respective diagnostic criteria, having been the primary educators among survey respondents (with roughly 51% of respondents having been trained by one or the other), however with the drastically different assessments each of these providers utilizes, it makes sense that there is confusion about reliability and validity of the tools used. Together with the fact that we have no evidence to promote agreement on which revision technique alleviates all known symptoms longitudinally, it can be ascertained that there is no solution to this issue at the current time.

The current literature combined with the data gained from this survey shows how complex of an issue it is when the anatomy and physiology of the mother impacts the ability for the baby to nurse, and sometimes allows a severely restricted baby to gain

weight just fine while nursing. A savvy and well-educated diagnostician will be able to weigh all the variables in order to tell when function is truly being impeded by the restriction. However, since they are not generally able to access the full breadth of information available among the varying healthcare professions' peer-reviewed journals, it would make sense for them to decide that a tie might not warrant revision if it only impacted their narrow scope of practice in a mild manner- but what of the individuals who have mild impacts in a wide range of areas?

There are an untold number of babies who breastfeed well enough to gain weight due to an active maternal milk ejection reflex- and what might be an oversupply if the baby were able to stimulate the milk more effectively. How many of these children ultimately have comorbid disordered sleep breathing with resulting behavioral issues and educational deficits? Is the fact that these issues might be prevented by resolving the restriction which caused the disordered sleep breathing irrelevant because the child breastfed "just fine" despite being tethered? Is it really the most appropriate response to give this child medication for attention deficits, anxiety or depression and machines to help compensate for the disordered sleep breathing when they could have had a revision in infancy that would likely have prevented these struggles?

Recommendations for current practice and future research

It has been clearly established that ankyloglossia is a hot-button issue for professionals working with breastfeeding families. Indeed, both Dr. Hazelbaker and Dr. Kotlow initially appear to be at either end of the worldwide controversy about tongue tie. Each set of diagnostic screening they have written has its strengths and weaknesses. The

HATLFF has been criticized for being difficult to understand and overly tedious to use in practice (Ingram, Johnson, Copeland, Churchill, Taylor & Emond, 2015) yet though attempts have been made to simplify or revise it, none have succeeded in making their way into the peer-reviewed scholarly literature of the world in any notable numbers. The Kotlow tool is quite provider-friendly in that it is simple to use but lacks in detailed explanation of how to use it properly, leaving providers wondering what is considered to be typical with regard to the presence of frenula. Additionally, as no easily accessible standardized training is available on either tool, it can be assumed that the majority of providers will not have access to instruction and education regarding how the tools work or why each criterion is important to the function of the tongue.

The current literature combined with the results of the current studies highlight how seemingly impossible it is for all the various fields of study to come together and agree upon the variables necessary to conduct a true comparison of one set of diagnostic criteria to another. Without a thorough understanding of the myriad of ways that ankyloglossia can impact the physiology of a person, and indeed their social existence as well, then the very idea that one can determine whether a revision was done correctly or not is called into question. With this in mind, one questions how diagnosis and treatment can be compared and contrasted without longitudinal studies which account for all the physiological impacts.

The further into the rabbit hole one travels, they can clearly see that the issue lies far beyond the criteria itself, as regardless of what criteria is used, the need to research what method should be used to revise the tie is of critical importance, as is the question of how to ensure that providers receive the training necessary to provide evidence-based

care to babies and children seen within their scope of practice. This naturally leads to the question of how does one determine that the tie was revised properly? Is successful breastfeeding the only necessary outcome? If not, which professional will be assessing for the myriad of other issues related to the tie? How can one truly assess whether the tie was revised properly if they are not also assessing other physiological factors such as orofacial development, airway and sleep progression, postural development, and suck/swallow function and the related compensatory behavior identification and treatment? How does one influence helping industries such that the evidence that is currently spread among otherwise unrelated industries of healthcare management can amalgamate into professional guidance documents for key industries, such as the AAP and AAFP, providers who are in the best position to screen infants, refer for special procedures and follow longitudinally? There are no easy answers to any of these questions. One can hope that future research can begin to systematically tackle one aspect at a time.

Why do more healthcare practitioners working with babies, regardless of whether they are breastfeeding, not use any established tools to assess for ankyloglossia? Is it indeed because there is no universally accepted diagnostic tool in existence? Why are some tools utilized with a greater frequency than others, and is any tool currently used superior to the other tools in existence, or does the use of any tool show superiority over the use of no tools at all?

It is the hope that this thesis will show that the age-old controversies surrounding ankyloglossia are impeding the dissemination of current evidence throughout the industry, and that the use of an evidence-based universal ankyloglossia screening tool is

critical. Universal screening will increase the rates of breastfeeding success and indeed, a lifetime of success as a healthy individual who is capable of sound sleep and less likely to have behavioral and educational deficits, and whose mother is significantly less likely to have postpartum mental health challenges as a result of failed breastfeeding.

Research into this area of the literature was attempted for the purpose of writing this thesis over the period of roughly 24 months, and no useful empirical data was found comparing any particular style of revision for tongue ties, as the variables- diagnostic criteria and revision method- are too widely variable to be able to compare beyond simply looking at the tools used (Francis, et al., 2015). This is one area of study in which the field would greatly benefit.

It has become clear in writing this thesis that the diagnosis and treatment of ankyloglossia cannot be compared and contrasted without longitudinal studies which account for all the physiological impacts so that the various healthcare industries can begin to agree upon a way to ascertain the efficacy of revision techniques. Information gained from following babies who have received different types of frenotomies (i.e. scissors to incise only the visible frenum versus laser to a diamond shaped wound in the submucosal lining under the tongue) over time to see the incidence of conditions which are causally related to ankyloglossia such as sleep disordered breathing, gut microbiome abnormalities and autoimmune dysfunction would provide a wealth of information that is currently unheard of within the field of ankyloglossia research. Once data such as this is obtained, then which school of thought seems to have the better long-term efficacy can be determined, looking beyond breastfeeding and focusing on whole-body health. At that point, public health would be better served by instituting universal screening protocols

within birthing facilities and babies can have these structural anomalies revised at or close to birth, preventing an exhaustive list of ailments down the line.

With the rate of diagnosis being as low as it is (at most, 10% of the population), and the rate of frenotomy unknown (but presumably not 100% of those diagnosed), it seems that the best chance for babies with ankyloglossia to grow up healthy and happy would be to have an increased rate of screening. As the assessments are so quick to administer and require no special tools, so there is little argument against universally screening infants at birth.

Indeed, the fact that the assessment occurs at all is clearly of more importance than which diagnostic tool is used in the current state of the world. If there is a breastfeeding challenge, sleep disordered breathing or excessive fussiness in a nursing infant and the tool indicates that there is a restriction in lingual function as a result of an overly tight frenulum, then the frenotomy should be performed and adequate follow up should be conducted, including common-sense active wound care management to prevent reattachment of the incised frenulum.

The fact that healthcare professionals seldom have access to peer-reviewed journals outside of their individual scope of practice inherently means that these professionals will not gain access to the full breadth and depth of impacts that ankyloglossia has upon not just the breastfeeding dyad, but in individuals with tethers across the lifespan. A legitimate response would be to not just rely upon the lactation professional or the pediatric dentist to be the leader of the team (though it is not common practice for healthcare professionals from varying fields to regularly work together in

order to provide continuous care for their patients) and to establish a TOTs specialty field to better integrate the research being done across the scholarly community.

The consequences of not having one central source of information and education about TOTs and the current available research were obvious in the short answer portion of the provider survey administered. While a fair amount of evidence-based information with regard to breastfeeding was known among providers, relatively few respondents were aware of the range impacts of ankyloglossia on immune function, postural and airway deficits, acid reflux, and difficulties bottle feeding. For the tethered baby whose growth is good due to the mother's vibrant milk ejection reflex, or due to the absence of a breastfeeding parent and a high-flow bottle nipple, their restriction is likely to be missed.

These consequences are causing a crisis within our healthcare industry today. There are providers who have sworn an oath to do no harm who are deliberately practicing medicine that is not evidence-based. There are providers who refuse to admit that there is even other knowledge in existence that they have not yet learned. There are providers who are giving out false information about ties and their physiological and psychological implications to those who have entrusted them with their child's health. Given the repercussions of missed tongue-tie diagnoses on the body and on society, these practices are simply unacceptable.

This discussion has come far beyond which tool is better- as most would agree that any tool is better than no tool at all, and that screening without using any consistent set of diagnostic criteria is simply negligent. This approach alone may improve breastfeeding outcomes by helping to dispel some of the common reasons for failed breastfeeding; a mother's perceived insufficient nipples/milk supply or that the baby

rejects the mother's breasts because of some perceived structural fault of the mother's body. It can reasonably be expected that if 10% or more of the population does have ankyloglossia, one can easily see how lowering the risk for sleep, speech, orofacial, and autoimmune dysfunction would also have a tremendous impact upon world health, beyond the plethora of benefits of a long and happy breastfeeding relationship between the mother and child.

APPENDICES

A. PARTICIPANT INSTRUCTIONS



**Graduate Program, Health & Wellness:
Maternal Health and Lactation**

Mary Miller, BA, CLC, MCH, CPD, CBC

Mary.miller@email.myunion.edu

(518) 506-8457

Hello! Thank you for participating in this research study. This will help me complete my Master's Thesis I am writing about the diagnostic tools for ankyloglossia (tongue-tie), the controversy within the field of ankyloglossia professionals and its impact on the breastfeeding dyad.

You'll find you've got two assessments for ankyloglossia (tongue tie) attached. The first, the ATLFF, is a detailed evidence-based assessment that scores a baby's tongue in both appearance and function. The second is a simpler experience-based assessment that gauges the tongue's appearance only. Instructions on how to use both assessments are detailed below.

Through the course of the study, you'll assess each baby born in your practice for ankyloglossia whose mother plans to breastfeed, using each assessment tool in an alternating fashion (i.e. one baby born will have the Assessment Tool for Lingual Frenulum Function (ATLFF) used, the next will be assessed using the Kotlow tool, and so on). After assessing the baby, you may A) complete all relevant portions of the data collection sheet or B) complete only the assessment portion of the sheet.

By the 6 week follow up appointment, the rest of the sheet will be completed for each client you serve. You may return the data collection sheets to me as you complete them if you wish (you may send them electronically or I can pick them up from your office). You may make as many copies of the assessments or collection sheets as you wish (and if it is easier for you to use one sheet per client rather than one sheet for multiple clients, this is okay too).

The study will continue through a 2-3 month period. My goal is to have 50-75 babies assessed between the three birthing provider sites. Thank you for helping move scholarly research on ankyloglossia forward! Your data will provide an invaluable contribution to the conversation about tongue ties and their impacts on breastfeeding families in Western NY and beyond!

B. ATLFF EXPLANATION AND FORM

The ATLFF, or Assessment Tool for Lingual Frenulum Function, scores 7 different function items and 5 appearance items. For more reading:

<http://www.alisonhazelbaker.com/shop/hatfff-hazelbaker-assessment-tool-for-lingual-frenulum-function>

The function items are as follows:

Lateralization (ability to move the tongue from side to side, assessed by placing a gloved finger along each side of the lower gumline and allowing baby to move their tongue towards the finger)

Lift of tongue (how high within the mouth the baby is able to lift their tongue towards the roof of their mouth)

Extension of tongue (the ability to move the tongue over the lower lip, over the lower gumline or neither)

Spread of anterior tongue (complete means the tip of the tongue can spread wide, whereas little or no spread means the tongue is unable to flatten out at the tip at all and is tethered in place by the frenulum).

Cupping of tongue (the baby's ability to curve their tongue up at the sides to cup a gloved finger inserted within the mouth)

Peristalsis (the wave seen in the Geddes ultrasound study done in 2010, which makes it possible to transfer milk from the breast to the baby's mouth. Full peristalsis means you can feel the tip of the tongue raise while the back of it lowers, and then there's a ripple as these positions are reversed, and then back again)

Snap back (clicking sound with sucking where suction is lost)

The appearance items are as follows:

Appearance of tongue when lifted (mostly in the tip of the tongue- is there dimpling or a heart shaped tip or is it round or square)

Length of lingual frenulum when tongue lifted (how much room you've got the tongue to stretch up with gloved fingers).

Attachment of lingual frenulum to inferior alveolus (whether the frenulum is attached to the back of the lower gums at its base)

Elasticity of frenulum (does it stretch at all)

Attachment of lingual frenulum to tongue (at which point the frenulum attaches to the underside of the tongue).

Assessment Tool for Lingual Frenulum Function (ATLFF)

Alison K. Hazelbaker, PhD, IBCLC, FILCA

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ASSESSMENT TOOL FOR LINGUAL FRENULUM FUNCTION

TM

<p>Assessment Tool for Lingual Frenulum Function (ATLFF)TM © Alison K. Hazelbaker, PhD, IBCLC, FILCA, 1993, 2009, 2012, 2016</p>	<p>Function Item _____ score: _____ Appearance Item _____ score: _____</p>
<p>Mother's Name: _____ Baby's name: _____ Date of assessment: _____</p>	<p>Baby's age: _____</p>
FUNCTION ITEMS	
<p>Lateralization 2 Complete 1 Body of tongue but not tongue tip 0 None</p> <p>Lift of tongue 2 Tip to mid-mouth 1 Only edges to mid mouth 0 Tip stays at alveolar ridge OR tip rises only to mid-mouth with jaw closure AND/OR midtongue dimples</p> <p>Extension of tongue 2 Tip over lower lip 1 Tip over lower gum only 0 Neither of the above OR anterior or midtongue humps AND/OR dimples</p> <p>Spread of anterior tongue 2 Complete 1 Moderate OR partial 0 Little OR none</p>	<p>Cupping of tongue 2 Entire edge with a firm cup 1 Side edges only OR moderate cup 0 Poor OR no cup</p> <p>Peristalsis 2 Complete anterior to posterior 1 Partial OR originating posterior to tip 0 None OR Reverse peristalsis</p> <p>Snap back 2 None 1 Periodic 0 Frequent OR with each suck</p>

(Continued)

APPEARANCE ITEMS (continued)	
<p>Appearance of tongue when lifted 2 Round OR square 1 Slight cleft in tip apparent 0 Heart shaped</p> <p>Length of lingual frenulum when tongue lifted 2 More than 1 cm OR absent frenulum 1 1 cm 0 Less than 1 cm</p> <p>Attachment of lingual frenulum to inferior 2 Attached to floor of mouth 1 Attached between the floor of the mouth and the ridge 0 Attached to ridge</p>	<p>Elasticity of frenulum 2 Very elastic (excellent) 1 Moderately elastic 0 Little to no elasticity</p> <p>Attachment of lingual frenulum to tongue 2 Between the tongue body-blade juncture and the tongue base 1 At the tongue body-blade juncture 0 In front of the body-blade juncture</p> <p>OR Notched tongue-tip alveolus</p>
Scoring/Frenotomy Decision Rule	
<p>14 5 Perfect Function score regardless of Appearance Item score. Surgical treatment not recommended.</p> <p>11 5 Acceptable Function score only if Appearance Item score is 10. Look for alternate cause of issues.</p> <p>,11 5 Function Score indicates function impaired. Frenotomy should be considered if management fails. Frenotomy necessary if Appearance Item score is ,8.</p>	

Clinical Lactation, 2017, 8(3), <http://dx.doi.org/10.1891/2158-0782.8.3.132>

Reference:

Hazelbaker AK: The assessment tool for lingual frenulum function (ATLFF): Use in a lactation consultant private practice. 1993, Pasadena, California, Pacific Oaks College

C. KOTLOW CLASSIFICATION INSTRUCTIONS AND FORM

The Kotlow Classification tool:

Type I: frenulum is attached to the tip of the tongue. Tongue may or may not have a cleft or heart shape. This frenulum will obstruct the ability to sweep a finger under the tongue and should be revised immediately.

Type II: frenulum is attached to the midline of tongue. This frenulum will obstruct the ability to sweep a finger under the tongue and mother should be told what symptoms to look for to decide whether tongue needs revision or not.

Type III: frenulum is attached to the midline/middle of the tongue- it may not be obvious at first glance. You may notice dimpling on the top of the mid-tongue when the baby is crying and trying to lift the tongue. This frenulum will obstruct the ability to sweep a finger under the tongue. Mother should be told what symptoms to look for to decide whether tongue needs revision or not.

Type IV: This may initially appear as there being no frenulum present; may look like a “guitar string” buried into the tissue under the tongue. You may also dimpling on the top of the mid-tongue when the baby is crying and trying to lift the tongue. This frenulum may obstruct the ability to sweep a finger under the tongue (but when pressure is applied under the tongue this “guitar string” may “pop out” and then cause the inability to sweep a finger side to side). Mother should be told what symptoms to look for to decide whether tongue needs revision or not.

For more reading:

<https://kiddsteeth.com/assets/pdfs/bf2017.pdf>

The **KEY** to examining an infant is correct placement of the infant on the examiner's lap with the baby's head facing the same direction as the examiner.



Reference: Breastfeeding Should be Fun & Enjoyable: Why does it hurt when I breastfeed? Retrieved from <https://kiddsteeth.com/assets/pdfs/bf2017.pdf>

The **KOTLOW** diagnosis and classifications of the newborn's lingual frenum is based upon the anatomical location of the tongue's attachment to the floor of the mouth.



Type **IV(1*) -total attachment with tip involvement



Type -III (2) Midline-area under tongue in front of salivary duct (creating a hump or cupping of the tongue)



Type II (3) Distal to the salivary duct but not at floor of the mouth. The tongue: may appear normal



Type I (4) Posterior area which may not be obvious and only palpable. Some are not visible if they are submucosally located.



Tight guitar string submucosal attachment

*The numbers in parenthesis are used primarily by some IBCLCs.
 ** The numbers outside the parenthesis are using the Kotlow protocol

How to find and identify the posterior tongue-tie attachment located at the base of the tongue.

Due to a lack of understanding this description of ankyloglossia or tongue-tie is usually is under reported and untreated.



Lawrence Kotlow DDS
 Submucosal Posterior tie, not visible when looking without pressing downward



Lawrence Kotlow DDS
 Using two index fingers with the infants head in you flap parent exposes sub mucosal posterior tongue tie !



Lawrence Kotlow DDS
 Submucosal tongue tie, visible when pushed downward

E. SURVEY

1	What is your profession?
2	Where are you located? (state/region/country)
3	How long have you been in practice?
4	Have you received any specialized breastfeeding training?
5	If so, did it lead to a certification or credential? Please select all that apply.
6	Do you have personal breastfeeding experience? (defined as the direct breast/chest feeding- i.e. not pumping/bottle feeding of yourself or the other parent of your children)
7	Do you have personal experience with tongue-tie, defined as a diagnosis of your personal children, nieces or nephews or close personal friends?
8	If yes, please describe your experience with ankyloglossia:
9	Do you assess for or diagnose ankyloglossia in your practice?
10	Have you ever received formal training or lectures on the subject of ankyloglossia?
11	If yes, from whom did you receive your formal training or lecture?
12	If you received your formal tongue-tie training or lecture from your professional association, from which association was it?
13	Did your formal tongue-tie training or lecture include instruction on the utilization of a diagnostic tool for your use to assess for ankyloglossia? Check all that apply.
14	Did you incorporate the use of this diagnostic tool into your practice?
15	Did you incorporate the content of this training into your professional practice?
16	If not, why?
17	If you only diagnose informally, what criteria needs to be met for diagnosis?
18	What are the physiological symptoms related to the following areas that you are aware of in regards to tongue-tie? If none, write "none."
19	What is your awareness of complementary therapies shown to provide habilitative support to individuals with ankyloglossia? If none, write "none."
20	Is there anything more you wish to tell us regarding the availability (or lack thereof) to learn about or quality of training related to tongue-ties, and how this relates to your professional practice?

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