ORIGINAL ARTICLE

Mothers' Perceptions and Experiences on Tongue-tie and Frenotomy: A Qualitative Study

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ABSTRACT

Introduction: Tongue-tie is a congenital condition of a thickened, tightened or shortened frenulum. This condition may cause breastfeeding difficulties to both mother and infant, such as ineffective suckling and painful nipple. In older children, it can cause speech difficulties. Although many studies have investigated the problems associated with tongue-tie and its treatments, there are limited studies on the mother's experiences of tongue-tie and post frenotomy. This study aimed to explore the mother's experiences of tongue-tie associated problems, frenotomy and the outcome. **Methods:** In-depth interviews were conducted in a one-on-one setting with fifteen mothers whose infant and children underwent frenotomy. Data were collected, transcripted, translated and analysed according to themes. **Results:** The analysis revealed a common story of stressful challenges and difficulties of breastfeeding. The mothers described that tongue-tie caused poor latching, nipple pain and bleeding, prolong feeding and lack of sleep. Their infant had poor weight gain, sleeping problems, insufficient milk transfer, fatigue and constant crying. For the older children, mothers complained of restricted tongue movement, difficulty in licking ice cream and speech problems. All of them agreed that the frenotomy procedure was easy, simple and less invasive and the outcome was positive. Furthermore, mothers continued breastfeeding without any difficulties and complications. **Conclusion:** Mothers in this study had difficulties with breastfeeding. However, all of the reported symptoms improved after frenotomy. They considered frenotomy was a simple and safe procedure that was highly recommended for symptomatic tongue-tie.

Keywords: Tongue-tie, Ankyloglossia, Frenotomy, Breastfeeding, Speech

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INTRODUCTION

Tongue-tie, the common name for ankyloglossia, is a congenital anomaly characterised by an abnormally short, thickened or tight lingual frenulum limiting the tongue's forward protrusion or lateral movement. The exact cause of tongue-tie remains unknown, but it is often hereditary, with a wide variation of incidence ranging from 1% to 10.7% in different populations (1-4). It is more common in males than females with no racial preference (4,5).

In infants with tongue-tie, mothers experience breastfeeding difficulties, including unsuccessful latching, insufficient milk transfer and nipple pain leading to infant poor weight gain, unsatisfied feeding, and early cessation of breastfeeding (5-8,9,10). Inadequate milk intake, mostly due to insufficient milk transfer resulting from unsatisfactory sucking, and breast and nipple pain are common reasons for stopping breastfeeding early. If the infant fails to latch correctly, mothers may develop sore nipples with bleeding or blisters. These issues are caused by a restricted tongue movement whereby the child cannot extend their tongue over the lower gum line to form a proper seal of the breast, as occurred in the tongue-tie condition (7,8).

In children, tongue-tie may cause mechanical problems, such as difficulty in licking ice-cream, inability to play wind instruments, speech impairment and dental problems (11-13). However, the problems caused by tongue-tie are debatable among various healthcare professions (14). Some studies showed that no significant association between tongue-tie and articulation problems and breastfeeding difficulties decrease with the help of supportive educational programmes (15,16). Studies and guidelines suggest that frenotomy should be performed by an experienced clinician once tongue-tie contributes to significant breastfeeding difficulties

(9,17,18). A thorough breastfeeding assessment using reliable tools is required to select an infant who may benefit from frenotomy (2).

Frenotomy is a simple, well-tolerated and safe procedure even on the first day of life by dividing the frenulum using either scissors, scalpel or laser, generally without any anaesthesia and few complications (5,15,19,20). Complications from frenotomy are uncommon. The most common is bleeding, which usually stops with local pressure. A Cochrane systematic review reported that no patients experienced any excessive bleeding, infection at the intervention site that require antibiotics and damage to the tongue or submandibular ducts following frenotomy (9).

Current evidence indicates that frenotomy improves breastfeeding and speech for children with greater severity and reduces the mother's symptoms (21-23). Others suggest that frenotomy does not improve breastfeeding but is associated with self-efficacy improvements (24). Thus, there is currently inconsistent evidence in relation to the benefits of frenotomy. With limited available evidence on the mother's experience and perception of tongue-tie and frenotomy in Malaysia, this qualitative study focuses on the mother's experience of the problems associated with tongue-tie, the treatment procedure and treatment outcome.

MATERIALS AND METHODS

This qualitative study where in-depth interviews were carried out on a focus group, was conducted at the Kulliyyah of Dentistry, IIUM, Malaysia, from March to October 2019.

All mothers whose children had undergone frenotomy from March 2017 until September 2019 were asked to participate in this study. They were referred to the Paediatric Dentistry Specialist Clinic by a lactation consultant, speech therapists and medical officers because of breastfeeding difficulties and speech problems. A thorough clinical assessment was conducted using the Hazelbaker Assessment Tool for Lingual Frenulum Function (HATLFF), and only cases that required tongue-tie release proceeded with frenotomy. All surgeries were performed by Paediatric Dental Specialists after consented by parents. The tongue was lifted using a grooved retractor while the infant/child was appropriately positioned and restrained without local anaesthesia except for an eight-year-old patient. The frenulum was snipped using sterile scissors (19). The incision was not sutured, and a direct pressure is then applied to the frenulum with a piece of gauze to stop the bleeding. The bleeding was minimal and well-controlled, and mothers are able to feed their children immediately afterwards.

On the review visit a day after frenotomy, mothers were taught on tongue-exercises technique to prevent frenulum reattachment by using her index finger to firmly push into the wound and upward movement five times per day for seven days (19). The lactation consultant was an International Board Certified Lactation Consultant (IBCLC) who also reviewed and referred cases to the Paediatric Dental Specialists. Upon frenotomy, patients were referred back to her for further evaluation of breastfeeding problems if any, and for continuous breastfeeding support.

Participation in this study was voluntary, and they were given research information sheets and required to sign consent forms. The study has been approved by the IIUM Research Ethics Committee (IREC) (Project number 2019-058).

A draft of open-ended questions was prepared prior to the interview session as a guidance to the interviewer. The mothers completed a written questionnaire regarding demographic data before the interview session. The interview was conducted in a one-on-one setting for about forty-five minutes. The discussion focused on the mother's experience of problems associated with tongue-tie, frenotomy procedure and treatment outcome to her and her children. The interviews were semi-structured, allowing mothers to lead the discussion and spontaneously raise topics of importance/ opinions without influence from the interviewer. The two interviewers were not the operators who did the frenotomy procedure. It was conducted in Malay language, and audio recorded was then transcribed verbatim by an independent transcriber who was not involved with this study. The transcripts were translated into English using the back-translation concept by an independent translator. The transcripts were verified twice by the interviewers against the recordings and were used as a primary data source.

Two authors independently draw out key codes from the primary data, and these codes were checked by a third author. Interpretation of the data was then discussed during face-to-face meetings and agreed upon by all research team members. The codes were categorised according to themes and sub-themes, and the connections between them were described and explained.

RESULTS

Out of twenty-one frenotomy cases, fifteen mothers agreed to participate in this study. Mothers tended to be highly educated and in employment, with six of them working in a health-related profession. Frenotomy was performed more frequently in male patients, and the age of the patients at the time of surgery ranged from 20 days to 8 years. All mothers breastfed their children except for a one-and-half and eight-year-old patient. There was no recurrent tongue-tie noted, and 33.3% of tongue-tie

cases ran in the family. The demographic characteristics of the participants are as in Table I.

Five key themes were identified: (1) tongue-tie associated problems to the mothers; (2) tongue-tie associated problems to the infant/child; (3) mothers' opinion on frenotomy; (4) mothers' opinion on treatment outcome; and (5) mothers' opinion on tongue-exercise (Table II).

Table I: Participants Characteristics (n=15)

Variable	n (%)
Age of mother	
20-30 years old	5 (33.3)
31-40 years old	10 (66.7)
Educational status	
Secondary school	1 (6.7)
Diploma	2 (13.3)
Bachelor's degree	10 (66.7)
Postgraduate	2 (13.3)
Mothers' occupation	
Health related	6 (40.0)
Non-health related	8 (53.3)
Housewife	1 (7.7)
Mothers' pre-knowledge about tongue-tie	
Yes	10 (66.7)
No	5 (33.3)
Gender of child	
Male	9 (60)
Female	6 (40)
Age of child during frenotomy	
0-6 months	12 (80)
1-2 years	2 (13.3)
8 years	1 (6.7)
Siblings with tongue-tie	
Yes	5 (33.3)
No	10 (66.7)

Theme 1 – Tongue-tie associated problems to the mothers

Thirteen mothers breastfed their children, and twelve of them had difficulties in breastfeeding.

Nipple pain

Seven mothers had nipple pain during breastfeeding with a few of them experiencing bleeding nipple.

"*There was a redness and pain on my nipple.*" (Mother1, aged 20-30, third child)
"*When I breastfed, I had breast pain. My nipple was bleeding.*" (Mother8, aged 31-40, third child)

Unsuccessful latching and prolong breastfeeding

They had difficulties in latching, causing prolong feeding of two to three hours per-feeding. These led to frustration, depression and lack of sleep. A few mothers started to give formula milk by bottle-feeding because they were worried about insufficient milk transfers despite adequate breastmilk production. The breastfeeding experience was different with tongue-tie children compared to non-tongue-tie for some mothers.

"*At first, I had a problem regarding the breastfeeding. I noticed that the breastfeeding did not work very well. Her attachment did not seem right.*" (Mother1, aged 20-30, third child)
"*My daughter had a hard time breastfeeding because she always missed latching on my nipple. She was always crying, and I needed to always breastfeed her.*" (Mother3, aged 31-40, third child)
"*At that time, it took me two to three hours to nurse my daughter.*" (Mother6, aged 20-30, second child)
"I *could not get enough rest. Every time he nursed, he*

Table II: Summary of identified themes and sub-themes about the mothers' experience on tongue-tie and frenotomy

Theme	Sub-themes	Mothers
1. Tongue-tie associated problems to the mothers	• nipple pain • Breastfeeding problem - unsuccessful latching, prolong breastfeeding, depress	• Mother1, 2, 4, 8, 10, 11, 13 • Mother1, 2, 3, 5, 6, 8, 11, 12, 14
2. Tongue-tie associated problems to the infant/ children	• Poor weight gain • Crying at night • Fatigue • Sleeping problem – prolong sleep, sleeping difficulty • Hungry/insufficient milk transfer • Restricted tongue movement • Difficulty in licking ice cream • Speech problem	• Mother1, 2, 3, 6, 8, 11, 12, 13 • Mother3, 4, 5, 11, 12 • Mother2 • Mother2, 6, 11 • Mother3, 5, 6, 8, 9, 10, 11, 12 • Mother2, 10, 15 • Mother15 • Mother7
3. Mothers' opinion on frenotomy	• Easy and simple • Harmless • Minimal bleeding • Normal crying • Necessary	• All mothers
4. Mothers' opinion on treatment outcome	• Improve in breastfeeding • Increase in weight • Improve in tongue movement, eating and speech	• Mother1, 2, 3, 4, 5, 6, 8, 9, 10, 11, 12, 13, 14, • Mother1, 2, 3, 6, 12 • Mother2, 7, 9, 15
5. Mothers' opinion on tongue-exercise	• Easy and simple • Compliant	• All mothers

would take almost two hours and then only slept for half an hour. After half an hour, he would wake up for feeding again." (Mother12, aged 20-30, first child)
"*I became depressed when I had problems with breastfeeding. Because he was always crying, I brought my child to a counsellor to discuss about his tongue and breastfeeding problems, and I had to use formula milk to deal with the problem.*" (Mother5, aged 20-30, first child)
"*This is my third child. My other children have never had a problem like this before. So maybe that's why I did not think this was normal.*" (Mother4, aged 31-40, third child)

Theme 2 – Tongue-tie associated problems to the infant/children
Mothers claimed that their infant had problems gaining weight due to insufficient breastmilk transfers, causing serious complications that resulted in hospitalisation for dehydration and jaundice. It also caused frequent crying, fatigue and lack of sleep due to hunger. Nevertheless, a few infants also tended to sleep a lot due to tiredness. The main problems for toddlers and older children were speech problems, restricted tongue movements, and licking ice-cream.

Crying and fatigue
"*My son has a hard time breastfeeding because she always misses latching on a nipple. She was always crying, and I need to breastfeed her always.*" (Mother3, aged 31-40, third child)
"*He slept a lot and was usually exhausted, which was an issue I noted. My breasts feel full, yet the baby refuses to sip the milk. He tried to nurse, but he didn't get enough milk, in my perspective. As a result, fatique and drowsiness develop, leading to dehydration, weight loss, and jaundice..*" (Mother2, aged 31-40, third child)

Insufficient milk transfer, sleeping problem and poor weight gain
Eight mothers claimed that their infant weight either did not increase, dropped or was not gained at a consistent rate.

"*My baby's issue was that she was constantly hungry and required frequent feedings..*" (Mother10, aged 31-40, third child)
"*When my baby was eight days old and taken to the hospital for jaundice, he was diagnosed with a tongue-tie. At that point, his weight had decreased from 2.8 kg to 2.6 kg in comparison to when he was born. As a result, he was admitted to a ward, and the doctor determined that his condition was caused by a deficiency of water in his body.*" (Mother2, aged 31-40, third child)
"*Because of the insufficient feeding, he frequently cried, causing him to sleep less. My son's weight did not rise either. He was unable to sleep due to hunger as a result of not receiving enough breastmilk.*" (Mother11, aged 20-30, first child)
"*The most serious issue at the time was that he had jaundice, and then he lost weight due to a lack of breastfeeding, resulting in prolonged jaundice.*" (Mother13, aged 31-40 years old, first child)

Restricted tongue movement and speech problem
Three mothers stated that their children had restricted tongue movements, although eating and drinking were not affected. Two of them noticed that their children had speech problems and the inability to lick ice-cream.

"*I only noticed that when I told him to stick out his tongue, the tongue looked like M-shaped. Then, when I told him to lick an ice-cream, he could not lick it properly. So instead of licking, he put the ice cream directly into his mouth and ate. I also noticed that the words that he could pronounce were limited compared to his older sister during this age. So, I started to worry that this tongue-tie could delay and slow his speech progress.*" (Mother15, aged 31-40, third child)
"*His speech was slurred. He could not say the words that had letters L, R and S perfectly.*" (Mother7, aged 31-40, third child)

Theme 3 - Mothers' opinion on frenotomy
All mothers agreed that the frenotomy procedure was easy, simple, quick, harmless and was necessary to their children. They recommended it to be done as soon as possible. There was minimal bleeding after the procedure, but it stopped after a while, and they could immediately breastfeed their children after the frenotomy procedure without any complication. The frenotomy went well without any further difficulties.

"*I realised that the procedure was simple. ……The bleeding was not much…*" (Mother2, aged 31-40, third child)
"*I am grateful and highly recommend this procedure. It is recommended that this procedure be performed as soon as possible after learning about the condition of the tongue-tie.*" (Mother5, aged 20-30, first child)
"*The baby was crying because we restrained him and the blood was little, not much, and only for a moment.*" (Mother8, aged 31-40, third child)
"*In my opinion, for me who did not know about this procedure, I felt sorry for the baby at first. But it turned out to be okay. The procedure was not too complicated. We needed to provide cooperation for the benefit of our baby.*" (Mother12, aged 20-30, first child)
"*I did not encounter any problems after the procedure.*" (Mother9, aged 31-40, second child)

Theme 4 - Mothers' opinion on treatment outcome
All mothers expressed their happiness with the outcome of frenotomy as their problem solved.

Improve in breastfeeding problem
All problems related to breastfeeding, including nipple pain, bleeding nipple, ineffective latching and

insufficient breastmilk transfer, were resolved after frenotomy.

"*The most noticeable change was that he could already suck better. Previously, for three months he had been used to unsuccessful sucking. In addition, I no longer felt pain while breastfeeding.*" (Mother4, aged 31-40, third child)
"*After undergoing the procedure, my daughter had no problem at all. She could latch to the breast well. The condition of her tongue also had changed, she could already stick out her tongue.*" (Mother9, aged 31-40, second child)
"*Immediately after the procedure, I cried because my daughter could breastfeed properly. I could see the difference in how she was breastfeeding compared to before the procedure, and I was very grateful. Until today, she can still breastfeed…….. The differences before and after the procedure are very significant.*" (Mother3, aged 31-40, third child)
"*The result is very satisfying. At the end of the procedure, the doctor asked me to breastfeed, and I was able to nurse comfortably. There was no pain, and my child could latch onto the breast very well. He also could sleep well because he had enough breastmilk.*" (Mother11, aged 20-30, first child)

Increase in weight
The weight problem was solved as the infants were full and satisfied with each breastfeeding, resulting in less crying and normal feeding time.

"*I can see that my child is already well-fed. Her weight has increased too.*" (Mother6, aged 20-30, second child)
"*My daughter looks very happy after the procedure. Every time she breastfeeds, she would be full, and she can sleep peacefully. She no longer cries and whines. Her weight has been increasing successfully to this day. She is now five months old and weighs over 6kg.*" (Mother3, aged 31-40, third child)

Improve in speech and tongue movement
Mothers agreed that frenotomy led to the free movement of the tongue; hence their children could stick out their tongue and licking ice-cream. For the eight-year-old child, the mother believed that he required further help to correct his pronunciation despite some improvements after frenotomy.

"*It's only been two weeks, but I could say that there has been a progression and improvement. When we told him to stick out his tongue, he showed some effort to stick it out. He tried to stick his tongue out and to lick, and he can mumble a lot now.*" (Mother15, aged 31-40, third child)
"*There seems to be an improvement in pronunciation after the procedure but provided that the child practices pronunciation regularly.*" (Mother7, aged 31-40, third child)

Theme 5 - Mothers' opinion on tongue exercise
All mothers thought that the exercises were simple and easy to practice. They understood the reason for performing the exercise.

"*I was compliant to the exercises, and it was easy to do. My husband also helped me in doing that. We had no problem with the exercise.*" (Mother4, aged 31-40, third child)
"*The doctor taught me to do the tongue exercise because it prevented the tongue-tie from recurring. Furthermore, one of the goals was to train the muscle of the tongue to be strong so that he could breastfeed properly.*" (Mother8, aged 31-40, third child)

DISCUSSION

Tongue-tie is a congenital anomaly that can be isolated or associated with other craniofacial abnormalities. It has a hereditary nature, occurs more commonly in males than females and has been suggested to be related to the X-chromosome (25, 26). In this study, males (60%) are more affected by females, and five children (33.3%) had siblings with tongue-tie, which showed a sign of inheritance. This finding was consistent with the previous study, which discovered that positive family history was found in 10% to 53% of the subjects (25). Before performing frenotomy, two-thirds of the mothers in this study had prior knowledge of tongue-tie and frenotomy. As a result, they had a favourable attitude and perception of frenotomy, which aided them in making their decision.

This qualitative study delivered valuable insights from the experience and perception of mothers on the impact of tongue-tie and frenotomy on them and their children. As concluded by previous studies, tongue-tie caused breastfeeding difficulties, mainly nipple pain, unsuccessful latching, insufficient milk transfer to the infant, ineffective suckling; the mothers in this study experienced the same problems (Table II) (7,9). They were very motivated to fully breastfeed their infants as they were aware of all the advantages and recommendations to exclusively breastfeed for a 6-month and the complementary feeding of up to two years old (27,28). Early weaning of breastfeeding is caused by multiple factors, including an insufficient offering of milk during the first month and nipple trauma (29-31). Therefore, some mothers in this study started to give formula milk and, at the same time, looking for a way to continue breastfeeding, prompting them to seek help from health professionals. Only through a competent health professional, the problems of tongue-tie can be addressed and managed. A lactation specialist is required to firstly teach mothers the correct way of successful breastfeeding. If the problem persists, frenotomy is suggested (2,32). In this study, all infants aged 0-6 months were referred by a lactation consultant who already consulted them about breastfeeding. The

consultant was one of the researchers who also reviewed and assisted them with breastfeeding and weight gain after the frenotomy procedure.

There are various controversial opinions regarding the causal relationship between tongue-tie and speech limitation. Nevertheless, a slight difference in pronunciation cannot always be diagnosed as a speech problem. Hence, frenotomy is only recommended when tongue-tie significantly affects speech (33). Restricted tongue movement will cause difficulty in pronouncing "s, z, t, d, n, l, j, zh, ch, th, dg," especially in the production of lingual-alveolar sounds (particularly/l/) and interdental sounds (voiced and voiceless/th/) which require maximum elevation and protrusion of the tongue (34). For this study, an eight-year-old male was referred by a speech therapist due to the difficulty in the pronunciation of L, R and S; hence, frenotomy was recommended. Following the frenotomy procedure, he was under the care of the speech therapist to further improve his pronunciation.

All mothers in this study agreed that the frenotomy was simple, easy and harmless. The tongue exercise also was easy to perform, and they were motivated to do it. They highly recommended frenotomy to treat symptomatic tongue-tie, although minor complications occurred such as minimal bleeding and crying (9, 19, 20). In this study, only minor complications occurred, which was very minimal bleeding and stopped after direct pressure using gauze on the incision site. All infants and children cried during the procedure, but it was only a short time and under control. The crying ended once mothers breastfeed their infant immediately following the procedure after the bleeding stopped. Conversely, other studies reported that frenotomy caused complications such as poor feeding, respiratory events, pain, bleeding and weight loss (36). In infants, frenotomy is usually performed without analgesia or anaesthetic (19, 20). Except for an eight-year-old, no local anaesthesia was administered in this study, and the pain was not one of the study's subthemes.

Frenotomy positively impacted all mothers and children in this study. The mothers were happy with the outcomes, and all their problems were solved with tremendous improvement in breastfeeding. Their infant weight increased; accordingly, the mother's depression and stress were eliminated. This has clinical significance for encouraging breastfeeding continuation (27,28). There were some improvements in pronunciation, but further help was required. Frenotomy followed by speech therapy is required for optimum results, especially for older children (35). Post-frenotomy, children can stick out their tongues freely and lick an ice-cream. Social and non-speech-related problems, such as playing wind instruments due to limited tongue mobility and untreated tongue-tie, may not become a concern until late childhood (35).

This formative qualitative study is one of only a few in Malaysia that explored the effect of tongue-tie and frenotomy from the perspectives and experiences of mothers. There are, however, a few limitations. The participants were from one centre and included those willing to participate only; hence, there was a limited number of participants. The view, therefore, cannot be generalised across contexts.

CONCLUSION

The mothers in this study experienced breastfeeding difficulties. They felt demotivated and stressed to continue breastfeeding. Their children underwent poor weight gain and articulation problems. However, after frenotomy, their breastfeeding improved significantly, and the pronunciation difficulty saw promising results. Frenotomy is a simple and safe procedure, and it is recommended for symptomatic tongue-tie.

Further research involving a larger sample size at a national level is necessary to find the prevalence of tongue-tie and its effect on children and mothers in Malaysia. Furthermore, a study involving the health care profession on their perception and practice of tongue-tie management is needed with a hope that knowledge and a high standard of management can be imparted. The effect of tongue-tie on speech is also worth finding. This is to ensure the accurate recommendation and evidence-based decisions can be made earlier.

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