# The value of frenotomy for ankyloglossia from a parental perspective

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#### **ABSTRACT**

**AIMS:** We sought the parental experience of the effects of frenotomy in the presence of ankyloglossia by exploring the reasons for seeking frenotomy, impressions of its value and its impact on breastfeeding.

**METHOD:** A prospective survey of infants receiving frenotomy in a general practice in Palmerston North was undertaken. Infants aged under six months with confirmed ankyloglossia via a GP and lactation consultant were included. One hundred and seventy-six children met the study criteria. Parents completed a pre-procedure questionnaire and received a follow-up phone call.

**RESULTS:** Results demonstrated that 97% of parents would seek out frenotomy again in similar circumstances. Initially, 93 mother-infant pairs (53%) were not fully breastfeeding; post frenotomy, 33 of these pairs were able to start fully breastfeeding. One hundred and thirty-two pairs showed no change in feeding method. Nine pairs deteriorated from partial breastfeeding to artificial feeding, and two pairs deteriorated from fully breastfeeding to artificial feeding. Both feeding time and nipple pain improved post-frenotomy. Eighty percent of parents reported a moderate or significant improvement in their presenting issue, and 77% reported moderate to significant improvement in feeding quality. There were no major complications.

**CONCLUSION:** Frenotomy was reported to be beneficial, with a high level of parental satisfaction and improvement in rates of full breastfeeding and feeding duration, as well as a reduction in nipple pain. Parents were willing to go to significant lengths to access the procedure.

B reastfeeding rates in New Zealand have gradually increased over the past decade, with gains seen in exclusive breast feeding at three and six months.¹ There are, however, women who initiate breastfeeding, but subsequently cease. These causes of breastfeeding cessation are multifactorial and can include nipple pain, latching issues, poor weight gain and prolonged feeding duration.² Previous research has linked ankyloglossia to these issues and to breastfeeding cessation.³-11

Ankyloglossia is a congenital condition in which a shortened lingual frenulum prevents normal tongue protrusion beyond the lower lip, or prevents sufficient elevation for effective breastfeeding. 3,12,13 Ankyloglossia is present in 1–11% of infants, and is often asymptomatic with approximately one-quarter experiencing feeding difficulties. 3,5,14-21 Frenotomy is the surgical release of ankyloglossia, usually

only performed when there is a feeding-related indication.

There are five widely accepted randomised controlled trials regarding frenotomy and its effect on breastfeeding, with a combined population of 302 infants. <sup>14</sup> NICE interventional procedures guidance [IPG149] states: "Current evidence suggests that there are no major safety concerns about division of ankyloglossia (tongue-tie) and limited evidence suggests that this procedure can improve breastfeeding. This evidence is adequate to support the use of the procedure provided that normal arrangements are in place for consent, audit and clinical governance." <sup>22</sup>

The main aim of this project was to determine parental satisfaction or dissatisfaction, and the self-reported benefits or harms following frenotomy. In addition, we analysed how many mothers commenced fully breastfeeding post-frenotomy (if not



able to prior). Secondary aims were to determine the degree of change in feeding time, nipple pain during breastfeeding and method of feeding post-frenotomy. Finally, we the sought to ascertain the proportion of parents who, if in similar circumstances again, would seek a frenotomy procedure. This measure was taken as an overall indication of satisfaction or dissatisfaction with frenotomy.

# Methods

# Participant/subject

The study participants included infants receiving a frenotomy at Hokowhitu Medical Centre, located in Palmerston North, New Zealand, where a lactation consultant and a general practitioner (GP) with a special interest in ankyloglossia accepts referrals, assesses and potentially treats infants. The study enrolment period was the seven months between September 2016 and March 2017. The inclusion criteria were: an infant aged under six months with confirmed ankyloglossia receiving a frenotomy for feeding-related issues. Infants were excluded if they had had a prior frenotomy (typically from another health provider) that had reattached and were thus requesting a second frenotomy.

#### Ethical considerations

Written consent was obtained from the infant's parent/caregiver, including consent for data analysis for research and/or audit purposes. The Ministry of Health, Health and Disability Ethics Commission, granted this research an out-of-scope confirmation.

# Protocol design and materials

The standardised data collection forms were designed by the primary investigator, two lactation consultants, the GP performing the procedure, a paediatrician and a senior statistician. The purpose of the questionnaire was to streamline consultations and to improve consistency of history-taking and data collection. The form included sections on patient demography, presenting complaints, current feeding method, clinician assessment, and procedure details. The form was used by the GP for several months prior to the beginning of data collection (see Appendices A and B).

In the vast majority of cases, the parent/caregiver bringing the child in for a

frenotomy was the child's mother, therefore for simplicity, 'parental' and 'maternal' are used interchangeably.

'Fully breastfed' was defined as the infant currently only breastfeeding, with no other liquids or solids except a minimal amount of water or prescribed medicines. Partial breastfeeding includes the intake of formula while concurrently breastfeeding. Artificial feeding is defined as solely bottle-feeding, whether with EBM or formula.<sup>23</sup>

# Preparations and procedure

Upon arrival at the practice, the infant's parent was given the questionnaire and was informed the full assessment and procedure would cost \$40. They were assessed by the lactation consultant (LC) who took further history and performed an initial examination. The GP then saw the infant, parent and LC together to clarify the history and perform a second assessment. The Kotlow diagnostic criteria24 was used to assess the degree of tethering (see Appendix C). It should be noted that under the Kotlow diagnostic criteria the most anterior tongue tie is a type 4, which is in contrast to some other grading systems in which a type one refers to frenulum to the tip of the tongue. If any disparity in professional opinion between the LC and GP occurred, they deliberated and came to a consensus. If history and examination indicated potential benefit from a frenotomy, the procedure was explained to the parent, and informed consent was obtained. No parents declined consent to be involved in this follow-up study. Mild analgesia was achieved by applying lignocaine gel, the tongue was elevated with either gloved fingers or a grooved indicator, and the frenotomy was performed with a scissor cut. The tissue was then blunt dissected/ stretched by finger to maximise tongue elevation. In Kotlow 1-2 cases (the most posterior/"deep"), the frenulum was injected with lignocaine and adrenaline by dental syringe, and a tissue crush was performed prior to the incision. Post frenotomy, the mother was then encouraged to breastfeed immediately if possible, with the support of the lactation consultant. The infant was checked frequently for bleeding. Parents were recommended to perform a simple tongue elevation stretch exercise on the infant prior to feeding at least four times daily for seven days.



Completed questionnaires were assessed by the primary investigator for inclusion eligibility. A clinical follow-up of all eligible patients was conducted by phone call. Up to 10 attempts were made to contact each infant's parent. During follow-up, a standardised questionnaire was used, designed to assess any new or ongoing issues with breastfeeding (see Appendix B).

All data were processed using EXCEL. Analyses were carried out by using a general inductive analysis approach.<sup>25</sup> Quantitative analysis was completed using Stata, and paired T-tests were completed when appropriate, with a p value of <0.05 was considered significant.

# Results

# Response rate

One hundred and ninety-seven infants were eligible for the study. Of these, 20 parents could not be contacted by phone and one could not speak English. The remaining 176 (89%) infants were successfully followed-up. The mean length of time between frenotomy and follow-up was 23 days, with a median of 20 days and a standard deviation of 12 days.

# Patient demography

The cause of the imbalance in gender (more males than females, see Table 1) is unknown, but has also been noted in other research.<sup>17</sup> The ethnic breakdown was

Table 1: Age, gender and ethnicity.

Patient demography	Mean	STD
Infant age	44 days	35 days
Maternal age	30 years	5 years
	Number	Percentage
Male infant	109	62%
Female infant	67	38%
Infant ethnicity		
Pakeha/New Zealand European	126	72%
Māori	27	15%
European (other)	10	6%
Asian	7	4%
Other	6	3%

similar to that of New Zealand as a whole, however Māori were under-represented at 15%, compared to 21% in the Manawatu.<sup>26</sup>

Parents became aware of ankyloglossia and were referred to the practice by a variety of means (see Table 2). Referral was predominantly by a lactation consultant, midwife or Plunket. The reasons given for seeking a frenotomy were varied (see Table 3). The issues most commonly reported were problems with latching and nipple pain.

Table 2: Source of referral for a frenotomy.

Referral source (some have multiple)	Number	Percent
Lactation consultant	81	46.0%
Midwife	48	27.3%
Plunket	25	14.2%
Self	16	9.1%
GP	5	2.8%
Chiropractor	3	1.7%
Paediatrician	3	1.7%
Osteopath	2	1.1%
Nurse	1	0.6%
Not stated	6	3.4%

# Location of participants

Results showed that 65% of participants lived outside Palmerston North, and 40% travelled over 200km for the appointment. Twenty-six participants reported having travelled from Wellington.

# Primary outcomes of frenotomy

Ninety-eight percent of parents reported that if they were in similar circumstances again, they would choose frenotomy.

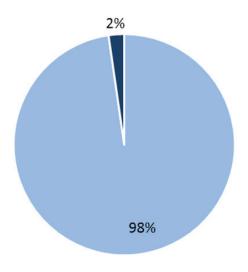
Prior to frenotomy, 93 participants (53%) were not fully breastfeeding. At the time of follow-up, 33 participants reported that following the frenotomy they had been able to start fully breastfeeding (that is 35% of those who were not initially fully breastfeeding).

Eleven mothers (6% of total) reported a decline in feeding method in the interval between frenotomy and follow-up. Two of these reported a decline from full breast-feeding to artificial feeding, while the remaining nine reported a decline from partial breastfeeding to artificial feeding.



Figure 1: Percent of parents who would still get the frenotomy done if in the same circumstances again.

# "If in the same circumstances again, would you have had the tongue-tie released?"



Would have a tongue-tie release again

■ Would not

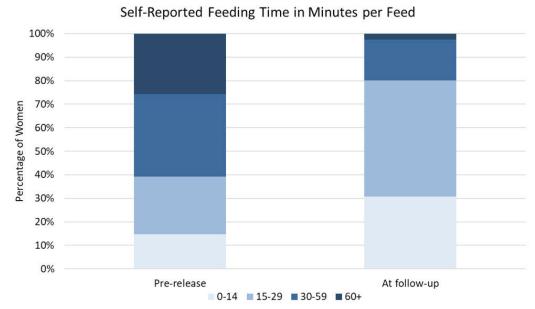
Table 3: Reasons given for seeking frenotomy.

Baseline characteristics		
Reason(s) given for attending assessment	Number	Percent
Issues with latching	115	65%
Nipple pain when breastfeeding	84	48%
Slow to feed	52	30%
Falling asleep breastfeeding	46	26%
Unsettled/fussy baby	37	21%
Poor weight gain	36	20%
Leaking milk while breastfeeding	36	20%
Not tolerating breastfeeding	22	13%
Windy	20	11%
Very frequent feeding	18	10%
Reflux issues	11	6%
Breastfeeding so painful nipple shields required	8	5%
Maternal milk supply issues	8	5%
Recurrent mastitis	6	3%
Cosmetic concerns	5	3%
Told to by a professional	136	77%
Parental concern of loud clicking while feeding	94	53%

NB: Multiple reasons were typically reported, so the total is greater than population.



Figure 2: Maternal report on feeding time pre- and post-frenotomy.



Minutes per Feed

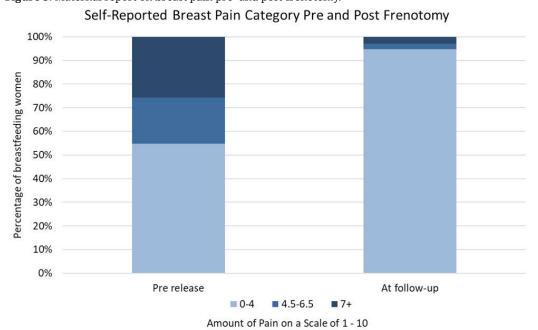
Out of the 11 mothers (6%) who reported a decline in breastfeeding, two stated they had already been planning to bottle-feed due to personal circumstances, and four mothers stated their milk supply had already nearly ceased prior to the frenotomy. These four mothers all stated that they wished they had undertaken the procedure earlier, since breastfeeding improved following it, but that they had waited too long, and their milk supply had already deteriorated prior to frenotomy. Therefore, undertaking the frenotomy may not have influenced the switch to bottle feeding in some cases.

# Secondary outcomes

There was a statistically significant reduction in reported feeding time. The pre-frenotomy average feeding time was 39 minutes, which reduced by 20 minutes post-frenotomy, halving the average time spent feeding at the time of follow-up (see Figure 2). This was highly statistically significant with the use of paired T-Test (p value <0.0001).

An improvement in nipple pain when breastfeeding was widely reported, with an average improvement of 3.3 points on the 0–10 pain scale (see Figure 3).

Figure 3: Maternal report on breast pain pre- and post-frenotomy.





# Degree of improvement by tonguetie grade

Figure 4 depicts the results when parents were asked: "before the tongue-tie release you reported having issues with [issue/s], overall how has that changed?" where [issue/s] are the issues reported at baseline as per Table 3. The degree of improvement reported was further disaggregated into improvement according to ankyloglossia grade in Figure 4.

Only one parent reported that the primary issue (in this case pain and latch difficulties) was worse at the time of follow-up. She reported that it had initially improved before deteriorating further and that the frenulum had reattached. She was considering a second attempt at a frenotomy.

If any improvement was reported, parents were asked how long before that improvement came into effect. The mean number of days to improvement was 2.3, with a median of two days and a standard deviation of 3.4 days.

Overall stretch exercises were reported as being continued for the recommended seven-day duration by 79% of parents. Of those who did continue the stretch exercises, 82% reported a significant improvement in the primary presenting complaint, compared to 51% of those who didn't.

## Complications

There were no life-threatening or persistent complications at time of follow-up reported. One mother stated that her 24-day

old infant, who was breastfeeding prior to frenotomy, had to be syringe fed for two weeks following the procedure due to an altered latch. After the two-week period the infant did re-learn to breastfeed. The mother then experienced a significant improvement in nipple pain relative to pre-frenotomy levels and at the time of follow-up was ultimately very happy with the results of the procedure. Eight other minor adverse events were reported: Four mothers stated their infant was either unsettled or had swelling under the tongue for 1-3 days, three mothers reported frenulum reattachment with their prior feeding issues returning, but at time of follow-up a subsequent release had not been performed. One mother reported their infants feeding deteriorated for one week before resolving.

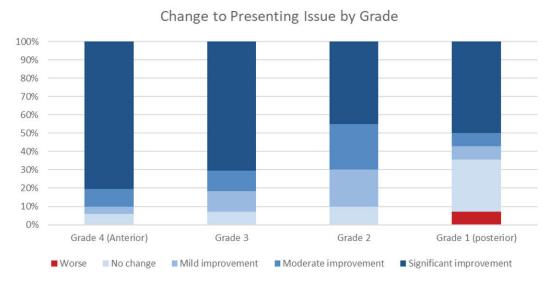
# Discussion

# Primary findings

This study is a prospective survey after frenotomy for ankyloglossia. There was no control population, and measurements were reported from the parental experience.

Overall, the parental participants had an overwhelmingly positive view of the effect of frenotomy, which is in line with other studies. With over 97% stating that they would do it again in similar circumstances, it shows the parents' self-perceived benefit was significant. This is despite parents witnessing an invasive procedure on their infant, potentially having to care for an unsettled infant, and bearing the financial

Figure 4: Change to presenting issue by ankyloglossia grade.





cost. These contextual factors place parents in a unique position to assess the overall value of frenotomy to their infant and themselves. This result also provides future parents considering frenotomy with a useful perspective given the divergent views on the procedure within the medical community.

A third of infants who were not able to fully breastfeed prior, improved to attain full breastfeeding status following frenotomy. This is a significant finding which shows a huge potential benefit for this subset of the population. The 35% that improved to full breastfeeding does not include those who showed an improvement but did not reach full breastfeeding status. These findings are consistent with other study findings, and can be summarised by a NICE guidance on Ankyloglossia: "By one month, the procedure proved to be effective in facilitating success of breastfeeding for 70% of the babies and was partially effective for another 20%."17,28,29

Over any period, there is a natural decline in the proportion of mothers breastfeeding, with approximately 6-10% mothers stopping per month.<sup>1,2</sup> A study based on the Growing up in NZ data showed that while 97% of women initially start breastfeeding, only half were exclusively breastfeeding to age four months, and 16% were exclusively breastfeeding until age six months.30 Thus, there was expected to be a proportion of mothers who would stop fully breastfeeding regardless. Clearly, mothers who present their infant for frenotomy are a preselected group with significant feeding issues, so the fact that they showed a definitive increase in breastfeeding is therefore highly noteworthy.

# Secondary findings

The primary purpose of this study was not to prove or disprove the procedure of frenotomy for ankyloglossia. It cannot, however, be ignored that there were clear reported improvements in many domains, and given the mean reported time to improvement following frenotomy being 2.3 days, where the mean age of the infant was already 44 days, this clearly implies a direct causal relationship from the procedure.

Feeding time was reported to have improved by 20 minutes on average.

Maternal self-reported pain scores related

to breastfeeding significantly reduced. It is expected that over time the normal infant would become more efficient at breastfeeding and nipple pain reduce, so exclusively attributing this to frenotomy must be done with caution. However, the reduction in nipple pain during breastfeeding post-frenotomy is consistent with other studies. <sup>6,8,11,14,28,31-33</sup>

Feeding quality overall also improved following frenotomy, with 55% and 22% reporting a significant or moderate improvement respectively.

Parents were asked the main reason(s) they sought frenotomy, and whether their particular issue(s) had improved or worsened. Figure 4 shows that there was a graduated response reported. Those infants with Kotlow grade 4 ankyloglossia (the most 'severe' and anterior version) were more likely to have a significant improvement in their presenting complaints, and as expected there was less change among the more posterior and 'mild' grade 1 group. This response indicates that the benefit is linked to the grade of ankyloglossia and is not a result of reporting bias or a placebo effect on the part of the parent.

At time of follow-up there were no ongoing significant adverse events reported from the frenotomy procedure, which is consistent with previous literature. 6.8,14,17,22,27-29,31,32

# Strengths and limitations

This study has a significantly sized population (176) and a high follow-up rate. There was no known selection bias from the doctor performing follow-up, and at least 10 attempts were made to contact the parent before recording them as a non-responder. Because much of New Zealand does not have a readily available publicly funded ankyloglossia frenotomy service this may have led to a delay in presentation, which may impact the generalisability of the results (with the mean infant age of 44 days, which is older than some literature). It is also likely that only more motivated parents would undertake finding a centre offering the procedure and organise to travel there. Expending this effort may make these parents more likely to believe that the frenotomy was beneficial to breastfeeding leading to a placebo effect. This



upfront parental investment may also have meant the treating GP is more inclined to offer frenotomy. However, these factors also potentially select for those with more severe feeding issues, and thus may have resulted in a population that is already likely to have worse feeding outcomes.

Hokowhitu Medical Centre accepts referrals for all grades of ankyloglossia, whereas some practices only attempt release on Kotlow grade 4, as many consider this a technically more simple procedure. This accounts for the apparent overrepresentation of posterior frenulum, and has diluted the improvement in our aggregated statistics, since the largest improvement was seen among grade 4 ankyloglossia.

Another issue for any study including subjective and self-reported data is the potential for reporting bias, where a participant may want to give a good (or bad) response to the follow-up doctor. However, as the follow-up call was by an independent doctor and not the operating clinician, this bias is likely less significant.

As mentioned previously, this paper has a limited role in confirming the efficacy of frenotomy. The biggest inherent issues are the unique and self-selected population, the potential for reporting bias and the potential for placebo effect. Results that can be seen to mitigate these concerns are the absolute improvement in fully breastfeed infants (which is much less likely to be effected by reporting bias); reported time to improvement being approximately two days (rather than instantly); and the differing outcomes based on grade (see Table 4), as it is inconceivable that the participants could knowingly experience a greater placebo effect in the Kotlow grade 4 category than grade 1. To fully account for bias a double blinded randomised controlled trial would be required, but doing so would be difficult given parents reluctance to risk being in a sham procedure group when they are experiencing very real challenge relating to feeding.

## Potential impact

This study shows there is considerable demand for frenotomy, and that this demand is not being met by the public sector. We note that 26 participants travelled from Wellington, our Capital city,

with tertiary medical facilities where one might expect to have such a simple service available. While there are private options for frenotomy in Wellington, several participants reported quotes in the range of \$200–\$800 for the procedure (this matches online available data). This cost, alongside travel requirements and subsequent delays to treatment, could create or perpetuate barriers to effective treatment for families with low incomes, limited transport options and poor health literacy.

Of concern is that only five of the 176 participants reported being referred or advised to investigate frenotomy by their GP. Although it was expected the majority of referrals would be from LMCs and LCs, after six weeks of age, the primary care of the infant is transferred to a GP. In this study, half of all infants were aged over six weeks, so it was surprising that GP referrals were rare. It is possible that parents are seeking support from other providers privately, or that GPs are not as familiar with the available options in cases of ankyloglossia.<sup>20</sup>

For clarity, the results of this study should not be used to recommend frenotomy to asymptomatic infants (those without feeding related difficulties), and should not be used to justify indiscriminate frenotomy if no issue exists.

# Conclusion

Frenotomy for infants with ankyloglossia and related feeding issues appears to be a safe and effective practice. Parents report high levels of satisfaction, improved quality of feeding and increased rates of full breastfeeding. A significant body of literature now supports frenotomy as being safe and beneficial in the context of feeding difficulties, and postponing this intervention while awaiting further research could mean infants with ankyloglossia and feeding issues experience avoidable negative outcomes.<sup>28</sup> In our society where the benefits of breastfeeding are widely understood to be beneficial, it is difficult to understand why access to frenotomy is so limited.

Further investigation into the availability, and disparities regarding access to frenotomy in the public sector of New Zealand should be undertaken.



# **Appendix**

Appendix A: baseline data

Tongue Tie Questionnaire Dear Parent/Caregiver, we appreciate your time in filling out this form today. This helps the doctor to get the information needed quickly so that more time can be spent discussing things that will help you / your child, and it will allow us to do an internal audit (and possible subsequent publication) to ensure that your child, and children like yours get the best possible healthcare at our practice. Some of these questions may not apply to you, but do your best to answer as many as possible. If we don't see you in the following week you may be phoned for a free phone follow-up. If you do not wish to be involved please tell the recweptionist or the doctor. Many thanks, Hokowhitu Medical Centre. Name of child: \_\_\_\_\_\_\_ Date of Birth: \_\_\_\_/\_\_\_ Boy / Girl City of residence: \_\_\_\_\_\_ Home Phone: \_\_\_\_\_\_ (please circle) (eg Palmerston North, Wellington, Marton) Cell-Phone: \_\_\_\_\_\_ Who referred you? Midwife / Lactation Consultant / Plunket / Dentist / GP / Other: \_\_\_\_\_\_\_ Mothers age: \_\_\_\_\_\_ Ethnicity: \_\_\_\_\_ Date: \_\_\_ / \_\_\_ / \_\_\_ First Appointment What is your reason for attending this appointment? (please circle any that apply) × Pain breast feeding × Baby not putting on weight × Breast feeding slow/takes a long time × Cosmetic concerns × Told to by professional × Baby not tolerating breast feeds × Baby falling asleep at breast × Very unsettled/fussy baby × Trouble latching/delatching × Clicking when feeding × Other: \_\_\_\_\_\_ How is your baby fed? Only breastfeeding / breastfeeding with top ups / expressed breast milk / bottle feeding /donor milk If not breast feeding, is that a *personal choice*, or did you have to change because of <u>feeding difficulties?</u> (please circle ONS) How long does the longest breast feeding typically take (ie when actually hungry)? \_\_\_\_\_\_ mins If bottle feeding, how long does the longest bottle feeding typically take? \_\_\_\_\_ mins How painful is breastfeeding? 0 - 1 - 2 - 3 - 4 - 5 - 6 - 7 - 8 - 9 - 10 (Not at all) (Extremely) Any other comments that may help us?



For Doctor to complete:			
TT Grade: 0 / 1 / 2 / 3 / 4	Ant / Post		
Tongue elevation: Good / Limited / Tight	Lip Fraenulum: Full eversion / Mild / Tight		
Procedure today: TT / LT / Not indicated / Deferred	Impression: U / L / M / H		
Immediate improvement? Y / N			
Comment:			

# Appendix B: follow-up collection

Date: Number		
Has there been any improvement in [issue/s] you reported since the release of the tongue tie?		
Significant / moderate / mild / none / worse		
If there was an improvement, how many days until it became apparent? Has it been sustained Y / N		
As a result of the tongue tie release were you able to start breastfeeding if you otherwise weren't?		
Y /N / NA		
Was there any change to feeding method following T/T? ( <b>now Brest / Bottle / NA</b> )		
You reported your feeding time was [state time],how long is it now?		
Do you feel that feeding improved? (unrelated to the issues that lead to frenotomy) <b>Sig/mod/mild/no/worse</b>		
How is the pain with breastfeeding now? / NA		
Did you follow the stretch exercises at all? Y / N How many days?		
Were there any complications you are aware of following the tongue tie release? N/Y		
If you were in the same circumstance again, would you have the tongue tie released? $ {f Y}  /  {f N} $		



# Appendix C: Kotlow diagnostic criteria

Kotlow grade	Description	Percentage in study (%)
Grade I	Located from the base of the tongue, halfway to the salivary duct	8
Grade II	Located between the back of the salivary duct halfway to the base of the tongue	23
Grade III	Located from the salivary duct half way to the tip of the tongue	40
Grade IV	Located at the tip of the tongue and extending half way between the salivary duct and tip of the tongue	29

## **Competing interests:**

Nil.

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