

A Qualitative Description of Mothers' Experiences Breastfeeding a Child with  
Tongue-tie

by

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### **Abstract**

Tongue-tie is characterized by an abnormally tight, short, and thick lingual frenulum restricting the tongue's movement. This functional impairment can hinder a child's ability to maintain an effective latch and suckle, and may lead to complex breastfeeding difficulties.

This qualitative research study focused on exploring the experiences of mothers who have breastfed or attempted to breastfeed a baby with tongue-tie, including how it affected their emotional well-being, relationships and future feeding practices, and to explore their perceptions of the healthcare received and the effect of the tongue-tie release.

A qualitative description study design was used. Two focus group sessions were conducted with a total of nine participants. Content analysis using constant comparison revealed a common story of struggle between the expectations of the mothers and their actual experiences of feeding a child with tongue-tie. The themes that emerged were emotional well-being, lack of priority for the breastfeeding relationship, lack of systemic support for tongue-tie, strain on relationships, and the mothers' perception of the child's experience pre and post tongue-tie release.

**Keywords:** breastfeeding, tongue-tie, ankyloglossia, infant feeding, qualitative description, focus groups

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**List of Abbreviations**

NL: Newfoundland and Labrador

WHO: World Health Organization

RCT: Randomized control trial

FiNaL: Feeding Infants Newfoundland and Labrador Study

HATLFF: Hazelbaker Assessment Tool for Lingual Frenulum Function

BTAT: Bristol Tongue Assessment Tool

CPS: Canadian Pediatric Society

CADTH: Canadian Agency for Drugs and Technologies in Health

IBFAT: Infant Breastfeeding Assessment Tool

LATCH (Breastfeeding Assessment Tool): Latch, Audible swallowing, Type of nipple, Comfort (breast/nipple), Hold (positioning)

BSES-SF: Breastfeeding self-efficacy scale- short form

SEM: Social Ecological model

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## **Chapter 1.0 Introduction**

### **1.1 Overview of the Thesis**

Chapter 1 of the thesis will present an overview of the background and rationale for this research project, the assumptions for the research approach, the problem statement, and introduce the research questions. Next, Chapter 2 will provide a review of the literature regarding tongue-tie and breastfeeding, more specifically the assessment and treatment of the tongue-tie, its effects on the mother, and the gap that remains in the literature. Chapter 3 will then offer an overview of the study design. It includes a general explanation of qualitative description research, as well as details specific to this study: sample selection, recruitment process, participants, data collection, data analysis, enhancing rigor in qualitative description, and ethical considerations. Chapter 4 will then address the participant characteristics and study results. The thesis then continues with Chapter 5, which will discuss the main themes that emerged from the data illustrating the participants' experience and the research questions that they answered in the context of the presently available literature. And conclusively, Chapter 6 will present the strengths and limitations of the present study, along with discussing areas for future research.

### **1.2 Background and Rationale**

The decision to breastfeed is usually not straightforward, and can be influenced by many factors, including personal preference and beliefs, confidence, education, and the influence of others.<sup>1,2</sup> A mother's choice, no matter the choice, can be heavily laden with guilt and pressure, from society and within.<sup>1,2</sup>

**1.2.1 Breastfeeding** Breast milk is the ideal food for the healthy growth and development of children, providing all necessary energy and nutrients. The World Health Organization (WHO) recommends exclusive breastfeeding for 6 months, and continued breastfeeding for up to 2 years or beyond with introduction of complementary foods.<sup>3</sup> Breastfeeding offers both short-term benefits (protecting against acute illnesses such as diarrhea and meningitis, as well as ear, respiratory, and urinary infections) and long-term benefits (protecting against chronic illnesses such as obesity, Type I & Type II diabetes) for the child.<sup>4-7</sup> The mother also benefits from breastfeeding. Research has shown that just after childbirth, breastfeeding can help stimulate uterine contractions, decrease postpartum hemorrhage, and speed up weight loss.<sup>8</sup> Additionally, a woman's risk of breast and ovarian cancers as well as osteoporosis may be reduced through breastfeeding.<sup>8</sup>

Despite strong recommendations from the WHO and many national health bodies in the Western world, breastfeeding rates, and in particular exclusive breastfeeding rates at six months, remain lower than recommended and can be highly variable across cultures and communities.<sup>2</sup> Furthermore, Newfoundland and Labrador (NL) has the lowest rate of breastfeeding initiation and exclusivity at 6 months in Canada.<sup>9</sup>

Research findings consistently show a positive association between breastfeeding and higher socio-economic status, older maternal age, and higher education. Reports from around the province confirm these findings.<sup>10</sup> In some regions of the province, the rates of formula feeding are very high, even though many women appear to know the benefits of breastfeeding.<sup>11</sup>

**1.2.2 Tongue-tie and Breastfeeding** Tongue-tie is characterized by an abnormally tight, short, and thick lingual frenulum (membrane under the tongue), which may result in restricted tongue movement.<sup>12,13</sup> This functional impairment can hinder a child's ability to maintain an effective latch and suckle, and may lead to complex breastfeeding difficulties.<sup>14-16</sup> There is a growing body of literature on the impact of tongue-tie on the physical act of breastfeeding.<sup>14-16</sup> In addition to difficulties with the mechanics of feeding, tongue-tie has also been noted to have a negative psychosocial impact on the breastfeeding relationship and maternal mental health.<sup>17</sup>

**1.2.3 Tongue-tie in Newfoundland and Labrador** The prevalence of tongue-tie has been reported to be within the range of 4.2% to 10.7% of newborns in North America.<sup>13</sup> The prevalence of tongue-tie in NL is unknown; however, awareness of this condition appears to be increasing in the public sphere and especially among mothers who are experiencing challenges with breastfeeding. As breastfeeding initiation rates slowly increase in NL, more mothers may experience challenges with breastfeeding, such as tongue-tie.

In 2012, some parents of children with tongue-tie created a social media community-based peer support group (Tongue Tied NL: Awareness, Education & Support). This group has grown to over 900 members in the five years since inception. Many parents within the group have raised concerns regarding the challenge to obtain timely and accurate identification and assessment of tongue-tie with evidence-based management and treatment options recommended. As a result, a number of mothers and babies have

travelled out of province for treatment that is not covered by the provincial medical care plan (MCP) (i.e., expenses paid out-of-pocket). The treatment for tongue-tie is a frenotomy/frenectomy or frenuplasty, more commonly referred to as a “release” or a “revision”. A simple incision of a tongue-tie with surgical scissors, laser, or a scalpel is the most common procedure.<sup>17</sup>

**1.2.4 The Breastfeeding Research Working Group** In 2009, the Baby-Friendly Council of Newfoundland and Labrador established the Breastfeeding Research Working Group (BF RWG) to evaluate infant and young child feeding practices in the province, and to gain a better understanding of the low breastfeeding rates in NL. The group conducted a longitudinal birth cohort study entitled “Feeding infants in Newfoundland and Labrador (FiNaL)”, which recruited pregnant women in their 3<sup>rd</sup> trimester (phase 1) with follow-up at 1-3 and 6-12 months postpartum (phases 2 and 3). The total number of participants enrolled was 1283. The primary objectives were to examine predictors for intent and non-intent to breastfeed, determinants of initiation and duration, and factors associated with early weaning and discontinuation of exclusive breastfeeding. Information was also collected on psychosocial factors (e.g., social supports, breastfeeding knowledge, attitudes towards infant feeding), prenatal education, birthing experiences (e.g., mode of delivery), and maternity care practices.

Preliminary findings from the FiNaL Study indicate that tongue-tie is a relatively common problem that presents significant breastfeeding challenges. In fact, 5% of respondents who attempted to breastfeed pointed to tongue-tie as a serious problem



affecting breastfeeding.<sup>10</sup> Interestingly, the FiNaL Study questionnaire did not solicit information on tongue-tie, nor did it define the term or discuss its influence on breastfeeding. However, in the comments section of the questionnaire, many respondents cited tongue-tie as an issue and reported a high level of frustration with access to adequate resources for assessment, diagnosis, and management.

A quote from a mother in the FiNaL Study:

[My child] had a lip tie and posterior tongue-tie. Nobody in the medical field, including lactation consultants, would take my concerns seriously. [Child] was not nursing properly, not gaining much weight, terrible gas pains, gagging, etc., and my nipples were severely damaged. We packed our bags and went to [private health care provider in the U.S.], who treated her immediately with 100% immediate improvement. I would not blame any mom for giving up on breastfeeding if they endured what my baby and I did [...] doctors need to stop saying 'it's just thrush pain' or 'switch to formula' - I was told both.

### **1.3 Assumptions for the Research Approach**

Based on the findings from the FiNaL Study, and the increasing number of issues cited by mothers on the social media support groups (Tongue Tied NL Awareness, Education & Support and Breastfeeding Support- NL), it was decided by the BF RWG that research in this area was a priority with the objective to examine the extent of tongue-tie and its impact on breastfeeding in our province. A simple exploratory study using a qualitative approach was chosen. It was thought a qualitative design would facilitate an initial

exploration of the impact of tongue-tie on mothers and breastfeeding. The assumptions made when starting this research project (based on what was learned from the online social media support groups and the FiNaL study) were: (i) tongue-tie has an effect on the mother-child breastfeeding relationship and the mothers' emotional well-being, (ii) the tongue-tie release treatment may have impact on the breastfeeding relationship, and (iii) mothers feel there is a lack of support available to them from the healthcare system. I developed my research questions to explore the mothers' perceptions of how breastfeeding a child with tongue-tie affected them and their child, as well as how they perceived the available supports from the healthcare system. A key goal was to provide a comprehensive description and summary of mothers' experiences and concerns with tongue-tie. To achieve this goal qualitative description was the approach used in the current study.

#### **1.4 Problem Statement**

The body of literature describing mothers' experiences with breastfeeding a child with tongue-tie is, to my knowledge, limited to one qualitative study conducted in Australia.<sup>17</sup> The study focuses on understanding the breastfeeding experiences of women whose infants were diagnosed with tongue-tie within three weeks of delivery and who had received supportive care from healthcare providers in the two weeks thereafter. It does not offer an in-depth exploration of the experiences of mothers who may have struggled with breastfeeding beyond the immediate post-partum period or those who were lost in the healthcare system. There is other literature available on tongue-tie and how it affects the breastfeeding relationship, but it is quantitative in nature. The proposed study will

describe the experiences of mothers feeding a child with tongue-tie and their experiences with access to care and available supports. It provides a critical first exploration of the experiences of mothers feeding a child with tongue-tie in our province.

### **1.5 Research Questions**

The purpose of this research is to explore the experiences of mothers who have breastfed or attempted to breastfed a child with tongue-tie for any period of time within the last 3 years. This exploratory study uses a qualitative descriptive approach to address the following research questions:

- 1) What are mothers' experiences of feeding a child with tongue-tie and how does this experience affect emotional well-being, relationships, and future feeding practices?
- 2) What are mothers' experiences with the healthcare services received?
- 3) What are mothers' perceptions of their child's ability to feed pre and post tongue-tie release?

## Chapter 2.0 Review of the Literature

This chapter will provide a review of the literature regarding tongue-tie and breastfeeding. The assessment and treatment of tongue-tie, the effects of tongue-tie on the mother, and the gap that remains in the literature will be discussed.

### 2.1 Tongue-Tie

Tongue-tie is a functional impairment that can hinder a child's ability to maintain an effective latch and suckle. During embryological development, the lingual frenulum fails to undergo apoptosis. The persistence of this embryological tissue results in the tongue-tie.<sup>18</sup> It is typically an isolated anomaly, but can be associated with other craniofacial abnormalities,<sup>19,20</sup> with an incidence of roughly 3 to 1 in males versus female.<sup>18,21,22</sup> A study conducted in British Columbia, using the perinatal data registry from 2004-2014 showed that the incidence of tongue-tie increased by 70% (5/1000 live births to 8.4/1000) over the ten-year period.<sup>23</sup> The authors also report that the population rate of frenotomy increased by 89% (2.8/1000 live births to 5.3/1000).<sup>23</sup> It has been suggested that this may be an underestimation, as their chart review data was limited to only tongue-tie diagnosis in hospital, a period of about 48 hours, which is a very small window to achieve a diagnosis.<sup>23</sup>

Tongue-ties can vary in severity, ranging from severely decreased and restricted mobility to a more flexible, less restrictive lingual frenulum. Depending on the extent of the mobility restriction, posterior and anterior tongue-tie can cause difficulties with

breastfeeding.<sup>16,22,24</sup> The anterior tongue-tie is the more common of the two and is found more easily on physical exam. Children with an anterior tongue-tie will usually present with a characteristic “heart-shaped tongue” when opening their mouths.<sup>18</sup> Anterior tongue-tie occurs when a lingual frenulum results in restricted tongue protrusion and movement that includes the tethering of the tip of the tongue.<sup>16</sup> The child with a posterior tongue-tie is more difficult to assess and is usually identified on manual inspection of the oral cavity. Posterior tongue-tie occurs when a lingual frenulum is thickened and more fibrous, anchoring the tongue to the floor of the mouth without the involvement of the tip of the tongue.<sup>16,22</sup>



*Figure 1. Image of a child with tongue-tie, used with permission by Dr. John Fayad, DDC*

Much research has been focused on tongue-tie and breastfeeding concerns, although less affected, bottle-fed babies may also experience problems with tongue-tie such as very slow feeding, excess dribbling, or excess wind.<sup>21,25-27</sup> Other research has focused on tongue-tie and speech-related issues (difficulty with articulation) and social concerns

related to limited tongue mobility. It has also been proposed that affected individuals may experience issues with licking, kissing, drooling, playing wind instruments, and oral hygiene in the long-term.<sup>28</sup>

## **2.2 Tongue-Tie and Breastfeeding**

The relationship between tongue-tie and its effect on breastfeeding is a debated topic among clinicians.<sup>26</sup> Approximately 12% to 50% of children with tongue-tie are reported to have feeding difficulties by their mother.<sup>14,17,18,24</sup>

There has been increasing emphasis on trying to improve breastfeeding rates in countries where the rates are low. As a result, there has been a focus on identifying mothers who want to breastfeed and giving them the help they need, which has prompted reexamination of tongue-tie as a clinical concern in breastfeeding.<sup>22,29</sup> Ineffective or prolonged feeding has been a common complaint expressed by mothers who have breastfed a child with tongue-tie.<sup>15</sup> Maternal reports of poor and shallow latch, as well as continuous and prolonged feedings have also been well documented in the literature.<sup>14,15,24,30</sup> Despite the initial intent to breastfeed, ineffective and painful breastfeeding may eventually lead these mothers to resort to formula or bottle-feeding.

Using ultrasound technology, Geddes et al<sup>31</sup> characterized the movement of the tongue when children nurse pre- and post-frenotomy. This study contributed to the current understanding of milk transfer whereby a vacuum is generated, drawing milk from the breast via negative pressure, and also demonstrated improved milk intake and milk-

transfer rate following frenotomy or tongue-tie release.<sup>32</sup> Therefore, the supply and demand cycle for production of breast milk is interrupted by the child's inability to extract the milk while breastfeeding. Normally, a child's increased transfer of milk during breastfeeding leads to a maternal hormonal cascade, resulting in greater milk production from the mother. Conversely, diminished sucking decreases a mother's milk supply, as the decreased mobility of the tongue interferes with the mechanics of breastfeeding.<sup>33</sup> Normally during breastfeeding, the tongue aids in pulling the whole nipple and part of the areola into the child's mouth and holds the milk before swallowing occurs.<sup>31</sup> The tongue also provides a combination of compression and suction of the nipple to express milk during breastfeeding.<sup>31</sup> Without full mobility of the tongue, the child is unable to maneuver an adequate portion of the nipple and breast into his or her mouth, resulting in a shallow latch.<sup>31</sup> The child may also use his or her lips or resort to biting the nipple, causing further injury that can result in bleeding.<sup>18</sup>

Several articles describe poor weight gain due to low milk intake and decreased transfer of milk when breastfeeding children with tongue-tie.<sup>14,17,18,24,34</sup> Children with tongue-tie may have decreased caloric intake affecting their growth, which may cause parents to get discouraged with breastfeeding and in turn decide to give formula to their child to prevent further weight loss.<sup>18</sup>

In an attempt to overcome the feeding challenges associated with tongue-tie, many parents opt to have their child's tongue-tie "released" or "revised". It should be noted, historically in the 18<sup>th</sup> century it was recommended to clip the frenulum when a child

presented with tongue-tie to help facilitate breastfeeding.<sup>35</sup> Furthermore, division of the lingual frenulum was usually performed routinely and early in infancy by the midwife using his/her fingernails.<sup>36</sup>

Currently, there are few validated tools to measure the severity of tongue-tie.<sup>37</sup> There is also no clinical standard for diagnosing tongue-tie,<sup>38</sup> but assessment tools such as the Hazelbaker Assessment Tool for Lingual Frenulum Function (HATLFF) and the Bristol Tongue Assessment Tool (BTAT) are cited in the literature. The HATLFF is considered comprehensive but difficult to use,<sup>39</sup> and the BTAT is noted to be simpler to ease implementation.<sup>40</sup>

There is a growing body of literature evaluating the effectiveness of frenotomy to improve breastfeeding outcomes. The Canadian Pediatric Society (CPS) states, “There is neither a universally accepted definition nor practical objective criteria for diagnosing tongue-tie [...] Clear criteria are needed for the diagnosis of tongue-tie”.<sup>12</sup> From a management perspective, the CPS does not routinely recommend frenotomy based on current available evidence, unless there is a clearly identified association between significant tongue-tie and major breastfeeding problems.<sup>12</sup> The CPS developed its statement based on literature available at the time, including three randomized control trials (RCT) deemed good quality,<sup>21,34,41</sup> and a systematic review.<sup>20</sup> In addition to these studies, they also assessed several other prospective cohort studies that have shown an association between tongue-tie and breastfeeding difficulties,<sup>39</sup> as well as the benefit of frenotomy in children with tongue-tie who present with breastfeeding difficulties.<sup>24,42-45</sup>



The first RCT cited in the CPS position statement was by Buryk et al<sup>41</sup> who conducted a randomized, single-blind, control study looking at the effectiveness of frenotomy versus a sham procedure. They enrolled neonates diagnosed with a significant tongue-tie, and having difficulty with breastfeeding or maternal nipple pain. They randomized 58 children, 30 to frenotomy and 28 to the sham procedure. The mean age of neonates at the time of enrollment was 6 days old. They found that both groups had statistically significant decreased average pain scores after intervention, however the reduction after a frenotomy was greater ( $p < 0.001$ ). Pain scores reduced from 16.77 (SD 1.88) to 4.9 (SD 1.46) and 19.25 (SD 1.9) to 13.5 (SD 1.5) in the frenotomy and sham groups before to immediately after the procedure, respectively, yielding an effect size of 0.38. The IBFAT score improved in the frenotomy group, without a significant change in the sham group. However, because the 27 participants in the sham group ended up receiving a frenotomy at or before 2 weeks after, means there was no long-term data available as the researchers were unable to keep blinding after the 1<sup>st</sup> procedure.

Berry et al conducted another RCT cited by the CPS.<sup>21</sup> They conducted a double-blind control study that looked at breastfed children with tongue-tie from 5–115 days old, using frenotomy as an intervention to help improve feeding. At a 1-day follow-up, 90% reported improved feeding following release and at 3-month follow-up, 92% still reported improved feeding, with 51% continuing to breastfeed. The authors concluded that there was a real, immediate improvement in breastfeeding, detectable by the mother, which was sustained and does not appear to be due to a placebo effect. However, the study was

noted to have limitations that included: no clear definition of tongue-tie, inclusion of only older children and outcomes over only one feed.

Emond et al<sup>34</sup> conducted the final RCT discussed by the CPS, which examined immediate frenotomy versus standard of care. They examined 107 term infants with a moderate tongue-tie and breastfeeding difficulty. They randomized 55 infants to the intervention (i.e., frenotomy) and 52 to the control group (i.e., lactation support). Their results demonstrated that at the 5 day and 8 week outcomes there was no difference found in latch scores, breastfeeding scores, and maternal self-efficacy and nipple pain scores. A particular strength of this study was its long-term follow-up; however, the results should be interpreted with caution as 32 out of 52 children in the control group crossed over to the intervention group and received a frenotomy on day 5 of follow-up. As the study followed an intention to treat analysis, data from these children were analyzed as if they remained in the control group therefore underreporting the differences in the two groups.

In addition, the CPS position statement also discussed the systematic review conducted by Francis et al.<sup>20</sup> This review examined surgical and non-surgical treatments for children with tongue-tie. The outcomes of interest were latch effectiveness, maternal nipple pain, breastfeeding effectiveness and duration. The researchers used two independent reviewers, and assessed 29 studies: 5 RCTS, 1 retrospective cohort and 23 case series. The authors concluded that a limited body of evidence suggests that frenotomy may be associated with mother-reported improvements in breastfeeding and nipple pain. As the

review was limited to short-term studies with very different methodologies, the strength of the evidence was considered low to insufficient.

The available literature has shown that the evidence for frenotomy for treating tongue-tie relating to breastfeeding difficulties is inconsistent.<sup>12</sup> The CPS has stated that there are many limitations with the current body of research on this topic, such as variability and poor definition for diagnosing tongue-tie, poorly defined outcomes, small trial size, and lack of demographic information.<sup>12</sup> Furthermore, the CPS adds that blinding of observers and mothers in such studies is very difficult to achieve.<sup>12</sup> In only one study, 100% of blinded mothers correctly identified the release of tongue-tie in their child.<sup>21</sup> The CPS suggests that careful consideration must also be given to the ability of a new mother to respond objectively about improved breastfeeding when her child has just undergone a procedure to which she consented. The CPS also notes that there is a lack of literature describing the 'normal' breastfeeding learning curve for mother and child.<sup>12</sup> They state that this “lack, along with the fact that a control group was seldom preserved during trials, makes it difficult to determine whether breastfeeding difficulties would have improved with time and conservative management (i.e., natural history)”.<sup>12</sup>

The Canadian Agency for Drugs and Technologies in Health (CADTH) has also conducted a review of the clinical effectiveness of frenectomy for the correction of tongue-tie.<sup>46</sup> This review includes two systematic reviews, one RCT, and four non-randomized studies. The authors of the CADTH review report that:

Overall, there is evidence that frenectomy is a safe procedure with demonstration of benefit for short-term breastfeeding effectiveness as perceived by the mother. There is less robust evidence, and thus, more uncertainty regarding objective and long-term measurements of breastfeeding effectiveness, reduction of maternal breast and nipple pain and feeding problems, increased continuation and duration of breastfeeding, and proper growth. Quality concerns with the literature included subjective outcome measures, poor generalizability, potential confounding, and unclear reliability of pooled and poor quality data. Frenectomy may benefit children of mothers who wish to improve their perceived breastfeeding effectiveness, at least in the short-term. Accordingly, older guidance states that when appropriate and conducted by a qualified practitioner, frenectomy is safe and likely beneficial to the patient.<sup>46</sup>

Considerable controversy also still exists in the medical community regarding the implications, diagnosis and management of tongue-tie. The lack of data on the natural history of untreated tongue-tie further propagates the uncertainty. Many within the pediatric community believe that conditions (such as tongue-tie) can improve spontaneously over time as a child grows and develops,<sup>47</sup> and some propose that a short frenulum elongates spontaneously due to progressive stretching and thinning of the frenulum with age and use.<sup>19,20</sup> Some clinicians are also concerned that a more liberal approach to frenotomy may result in ‘therapeutic creep’, with significantly more babies being subjected to the procedure unnecessarily.<sup>47</sup>

### **2.3 Mothers' Experiences with Tongue-tie**

In addition to difficulties with the physical act of feeding, qualitative research suggests that tongue-tie has a negative psychosocial impact on the breastfeeding relationship and maternal mental health.<sup>17</sup> Edmunds et al<sup>17</sup> collected data using focused interviews and, following transcription, were analyzed in the phenomenological tradition, which is to explore the meaning, examination, and description of the human experience to gain an understanding of what has occurred. There were 10 women who presented at a breastfeeding clinic with feeding problems. Their children were diagnosed with tongue-tie, and then were interviewed on 2 occasions. The results of the analysis exposed a tension between mothers' expectations and the breastfeeding challenges they faced. Their experience was characterized by 6 distinct phases described in the following themes: expectations; something is wrong; questioning, seeking advice, no real answers; symptoms and perseverance; approaching the wall—it's all too much; and finally, relief.

This study demonstrated the difficulties women experienced while trying to breastfeed a child with tongue-tie, which was very different from the "natural" experience they had anticipated. The authors also suggested that the mothers encountered health professionals who had limited knowledge of tongue-tie and its potential effect on breastfeeding and were unable to provide appropriate advice concerning their breastfeeding difficulties. The study findings also revealed that following treatment with release, their breastfeeding experience improved dramatically.

The authors concluded that the reported incidence of tongue-tie was significant, and that early identification and prompt and effective management would contribute to improved breastfeeding. However, the study does not explore the experiences of mothers in the depth that is proposed in the current study, nor does it explore the experiences related to access to care and available supports as this study will do.

When assessing the effectiveness of frenotomy for the correction of tongue-tie, many of the studies assess breastfeeding effectiveness through such tools as the Breastfeeding Self-Efficacy Scale Short Form (BSES-SF), the Child Breastfeeding Assessment Tool (IBFAT) and LATCH score. The BSES-SF is a validated, 14-item survey that measures breastfeeding efficacy and confidence using Likert scale responses between 0 (“Not at all confident”) and 5 (“Very confident”). Scores are summarized (range, 0–70), where higher scores indicate lower breastfeeding impairment and higher confidence.<sup>48</sup> The IBFAT contains 4 scored items assessing the child state: child readiness to feed/arousability, rooting, fixing (time needed to latch to the breast), and suckling pattern. Each item is assigned a score from 0 to 3, with 3 representing the highest item score.<sup>49</sup> LATCH is a breastfeeding charting system that provides a systematic method for gathering information about individual breastfeeding sessions. The system assigns a numerical score, 0, 1, or 2, to five key components of breastfeeding. Each letter of the acronym LATCH denotes an area of assessment. "L" is for how well the child latches onto the breast. "A" is for the amount of audible swallowing noted. "T" is for the mother's nipple type. "C" is for the mother's level of comfort. "H" is for the amount of help the mother

needs to hold their child to the breast.<sup>50</sup> The effectiveness of the procedure is also assessed through maternal reports of nipple and breast pain using pain score systems.

## **2.4 Gaps in the Literature**

The experience of the mother is a key element to assessing breastfeeding and tongue-tie along with proper treatment and management to better support families that are dealing with tongue-tie. The reasons mothers are choosing to have their child's tongue-tie "released" and are seeking support for issues that are causing distress to not only their child, but to themselves.

My thesis project is significant in a number of ways. First, it adds to the limited but growing body of literature examining child feeding within the province of NL. Secondly, it provides insight into the mothers' perceptions of access to care and available supports for children with tongue-tie in the province. Furthermore, in the study conducted by Edmunds et al,<sup>17</sup> the mothers interviewed were immediately post-partum, however, in the current study an attempt was made to recruit mothers who have been feeding their children for a much longer period of time. This is important as it adds to the literature on the long-term potential consequences of tongue-tie. Finally, it adds to the very limited qualitative research published, as almost all of the available research is quantitative in nature.

### **Chapter 3.0 Methodology**

The purpose of this study is to explore the experiences of mothers who have breastfed or attempted to breastfeed a child with tongue-tie for any period of time. An exploratory study using a qualitative descriptive approach was conducted to address the following research questions:

- 1) What are mothers' experiences of feeding a child with tongue-tie and how does this experience affect emotional well-being, relationships and future feeding practices?
- 2) What are mothers' experiences with the healthcare services received?
- 3) What are mothers' perceptions of their child's ability to feed pre and post tongue-tie release?

This chapter provides an overview of the study design. It includes a general explanation of qualitative description research, as well as details specific to this study including sample selection, recruitment process, participants, data collection, data analysis, enhancing rigor in qualitative description, and ethical considerations.

#### **3.1 Design of the Study**

**3.1.1 Qualitative Description** The fundamental purpose of most qualitative studies is to



“achieve an understanding of how people make sense out of their lives, delineate the process of meaning making, and describe how people interpret what they experience”.<sup>51</sup>

Qualitative description is a form of qualitative research that aims to describe the participant’s perceptions and experiences.<sup>52</sup> Other qualitative approaches often aim to develop concepts or theories and analyze data in a reflective or interpretive interplay with existing theories, whereas the final product of qualitative description is a description of participants' experiences in a language similar to the participants' own language.<sup>52,53</sup>

Unlike some qualitative methodologies (such as grounded theory) that are built on a particular constellation of procedures and techniques (e.g., memoing, axial coding, selective coding, etc.), qualitative description is grounded in the general principles of naturalistic inquiry.<sup>54</sup> As such, qualitative description utilizes a variety of sampling, data collection, and data analysis techniques, where the researcher studies something in its natural state and does not attempt to manipulate or interfere with the ordinary unfolding of events. Taken together, these practices lead to a comprehensive understanding of an experience, very often in the words of participants.<sup>54</sup>

The knowledge and use of qualitative description as a qualitative research approach in health research is limited and is often criticized for being too simple and lacking rigor.<sup>53,55</sup> However, proper use of the method can be quite useful for data tailoring within clinical interventions, and for needs assessments and questionnaires in mixed method studies or in relation to small independent research projects.<sup>52</sup> Qualitative description was seen as a good fit for this Master’s thesis given its aim of describing mothers’ experiences with breastfeeding a child with tongue-tie. In terms of a theoretical

framework, qualitative description is “founded in existing knowledge, thoughtful linkages to the work of others in the field and clinical experience of the research group”.<sup>52</sup> With regards to this Master’s project, my theoretical perspective taking on this research was based on what I had previously learned about tongue-tie and its effects on breastfeeding through reading the available literature, and the anecdotal stories I had heard from joining the online social media groups, and being a part of the BRWG. This study focused on understanding the experiences of mothers who breastfed or attempted to breastfeed a child with tongue-tie. It was through the open-ended questions asked during the focus groups and interactions among participants that I developed a greater understanding of the mothers’ experiences, the affects on their emotional well-being, perceptions of the healthcare system and available supports, and perceptions of tongue-tie revision on overall feeding practices.

**3.1.2 Sample Selection** Purposive sampling was used to select participants who could contribute detailed information to enhance our understanding of the experiences of mothers who had breastfed or attempted to breastfeed a child with tongue-tie. Purposive sampling has two principle aims, with the first being to ensure that the key constituencies of relevance to the subject matter are covered. The second is to ensure that, within each of the key criteria, some diversity is included so that the impact of the characteristic concerned can be explored.<sup>56</sup>

Potential participants were sent an inclusion criteria questionnaire (Appendix A) which asked for information on age of mother, level of education, age of child with tongue-tie,

the time period when the mother breastfed or attempted to breastfeed her child with tongue-tie and for how long breastfeeding took place. Participants were selected based on a list of four specific inclusion criteria. First, the mother had to be over the age of 19; second, the mother had to have a child diagnosed or suspected to have an anterior and/or posterior tongue-tie; third, the mother had to have breastfed or attempted to breastfeed a child diagnosed with tongue-tie for any period of time within the last 3 years. Finally, the mother had to be available for the scheduled focus group.

**3.1.3 Recruitment Process** Participants were recruited from two social media groups: (1) Tongue Tied NL Awareness, Education & Support and (2) Breastfeeding Support-NL. The administrators of these groups gave me permission to post the advertisement for the study (Appendix B). Potential participants were notified of the date and time of the focus groups, and efforts were made to ensure that each focus group was held at a time and place that was convenient for participants.

**3.1.4 Participants** The socio-demographics of the sample are presented in Table 1.

**Table 1. Participant Characteristics (n=9)**

<b>Characteristic</b>	<b>n</b>
<b>Age</b>	
25-34	6
Over 35	3
<b>Education Completed</b>	
College diploma	2
Graduate Degree	4
Professional degree <sup>1</sup>	3
<b>Marital Status</b>	
Married/Common-Law	9
<b>Residence</b>	
St. John's	3
Surrounding St. John's area <sup>2</sup>	6
<b>Annual Household Income/Year</b>	
\$30,000-\$60,000	1
\$60,000-\$100,000	3
Over \$ 100,000	5
<b>Current Employment</b>	
Homemaker	3
On maternity leave	2
Employed full-time	3
Employed part-time	1

1. Professional degree: MD, JD, etc.

2. St. John's surrounding area: Portugal Cove, Mount Pearl, Paradise

**Table 2. Participant's Children**

<b>Participant #</b>	<b># Of Children</b>	<b># Of Children Diagnosed with Tongue-tie</b>
<b>1</b>	2	2
<b>2</b>	4	3
<b>3</b>	1	1
<b>4</b>	1	1
<b>5</b>	2	1
<b>6</b>	2	1
<b>7</b>	1	1
<b>8</b>	1	1
<b>9</b>	2	2

As Table 1 illustrates, the participants were in the age range of 25 and older, were married or common-law, lived in St. John's and surrounding area, and were educated and relatively affluent compared to the rest of the population of NL. Therefore, our sample is indicative of a higher socio-economic class, living in an urban population.

As table 2 illustrates, the time of diagnosis for the tongue-tie ranged from one day to two years of age, with the majority of the participants' children (54%) being diagnosed between one day to two weeks of age. The diagnosis of tongue-tie was made by a pediatrician (n=2), family physician (n=1), lactation consultant (n=5), public health nurse (n=5), dentist (n=3), doula (n=1) or self-diagnosis (diagnosis by mother/parent of child with tongue-tie) (n=1). A number of participants mentioned that their child received a diagnosis from more than one person. Three participants went out of province for tongue-tie treatment. All of the participants (n=9) had decided to breastfeed when pregnant, and breastfed or attempted to breastfeed all of their children.

The group of nine mothers had the following in common: each had at some point breastfed or attempted to breastfeed their child, and at least one child had received a diagnosis of tongue-tie. Additionally, two of the participants had been diagnosed with a tongue-tie, and one participant self-reported tongue-tie. Among fathers/second parents, participants reported that one was diagnosed with a tongue-tie, seven had not been diagnosed, and one was unsure if they had been diagnosed. Two participants reported having a parent or sibling diagnosed with tongue-tie, and three were unsure if a parent or sibling had received a diagnosis.

**3.1.5 Data Collection** In qualitative description studies, data collection attempts to discover “the Who, What and Where of events” or experiences.<sup>53</sup> The data for this study were collected through two focus groups and a demographic questionnaire, which is consistent with qualitative description methodology.<sup>52</sup> Focus groups are characterized by the interaction of group participants *with each other* as well as with the researcher, and it is the collection of this kind of interactive data that distinguishes the focus group from the one-to-one interview,<sup>57,58</sup> as well as from procedures which use multiple participants but do not permit interactives.<sup>57</sup> A variety of communication strategies is important because people's knowledge and attitudes are not entirely encapsulated in reasoned responses to direct questions. Utilizing everyday forms of communication such as jokes, anecdotes, and loose word association may tell us as much, if not more, about what people “know”. In this sense, focus groups may “reach the parts that other methods cannot reach”<sup>58</sup> - revealing dimensions of understanding that often remain untapped by the more conventional one-to-one interview or questionnaire.<sup>58</sup> Moreover, people’s health beliefs, their ideas about what causes a disease or what cures an illness, the meanings they attribute to different parts of their bodies or to different medical procedures are not generated by individuals in splendid isolation. Such beliefs are forged and shaped in everyday social contexts.<sup>57</sup>

Furthermore, contrary to the common assumption that people will be inhibited by the presence of other group members, the group context actually facilitates openness and disclosure.<sup>57</sup> Participants not only help each other to overcome embarrassment, but they can also provide mutual support in expressing feelings which are common to their group

but which they might consider different or deviant from mainstream culture (or the assumed culture of the researcher).<sup>58</sup> In particular, social desirability may be less of a problem in focus groups than in one-to-one interviews. Several researchers have noted that, compared with interviews, group discussions tend to generate the expression of more ‘socially undesirable’ opinions and emotions.<sup>57</sup>

This enhanced disclosure is especially evident when sensitive issues are under discussion. Many focus group researchers report that when research participants share common experiences—in particular, painful or emotionally intense experiences (such as the mothers in our study), individuals typically offer considerable detail about such aspects of their lives.<sup>57</sup> This is especially true when their contributions are reinforced and their concerns legitimated by other group members. Moreover, it is commonly found that the less inhibited members of the group break the ice for shyer participants, and that one person’s revelation of ‘discrediting’ information encourages others to disclose similar experiences.<sup>57</sup>

Prior to starting the focus group, all participants were given the time to complete a demographic questionnaire (Appendix C). Once completed, I led the participants through various open-ended questions as outlined in the focus group prompts (Appendix D) but there was no predetermined sequence or expectation of what might be said. The focus groups lasted between 60-90 minutes and were audio-recorded with the consent of the participants. No identifying details were attached to the transcript. All participants were assigned a number.

**3.1.6 Data Analysis** The strategy of content analysis is used in qualitative description and is common to many qualitative methods.<sup>52</sup> Conventional content analysis is used in studies that aim to describe a phenomenon where existing research and theory are limited.<sup>54</sup> This approach fits our study well. The data set included audio recordings from both focus groups and their typed transcripts, nine demographic questionnaires that had been completed by each participant, and hand written notes by me as I conducted the focus groups. The hand written notes were referred to during data analysis to identify the questions that elicited the most emotional responses, the least emotional responses, and group dynamics (e.g., dominate personalities, shy speakers). Furthermore, my notes also included my own reflections on the conversation, such as specific “lingo” used by the group, topics that needed to be discussed further, or statements I needed further clarified. Following the analytic strategies proposed by Milne et al<sup>55</sup> for qualitative description, I began data analysis by transcribing the audio-recorded focus groups and identifying the individual voices of participants to link them with their demographic data and notes from each session. Two copies of each transcript were made: one as a master copy and one as a working copy which would be used to highlight key words and make notes in the margins.

I acted as the primary analyst and a member of my supervisory committee acted as the secondary analyst. The data were organized manually, and analyzed using constant comparison by both analysts. Constant comparison is a process where all the data relevant to each category are identified and examined, in which each item is checked or compared with the rest of the data to establish analytical categories, or themes.<sup>59</sup> The key



point about this process is that it is inclusive; categories are added to reflect as many of the nuances in the data as possible, rather than reducing the data to a few numerical codes.<sup>59</sup>

The credibility and accuracy of the data were improved by having the transcripts coded and analyzed by two coders working independently. We met regularly to identify major themes being generated by the initial independent coding and analysis. We followed the process of reading through all the scripts from the focus groups, then highlighting reoccurring words, ideas or images and grouping them into themes. From this we developed sub-themes that fell under larger themes and then described what these meant, and organized an initial coding template. Using this initial template, together we re-coded the transcripts to make sure the coding was consistent throughout the scripts. Discrepancies between any coding were discussed and resolved. We then developed a revised template through consensus and re-coded all transcripts with the final template, making sure to update the template as necessary.

**3.1.7 Enhancing Rigor in Qualitative Description** Qualitative description has been criticized for its lack of rigor and for being flawed in judgment of its credibility.<sup>52</sup> However, it is possible to establish both rigor and credibility in qualitative description.<sup>52</sup> Qualitative description is a method that affords a comprehensive summary of human experience without an in-depth level of interpretation.<sup>53</sup> The goal is to stay close to the surface of data while capturing all the elements of that experience, and the inherent scientific rigor is a reflection of a researcher's ability to achieve that goal.<sup>55</sup> As proposed

by Whittemore et al<sup>60</sup> the strategies to enhance rigor within qualitative description are *authenticity, credibility, criticality* and *integrity*. As Milne et al<sup>55</sup> discusses, these criteria are highly interrelated, and therefore should be discussed in pairs. The credibility of a qualitative study is a factor of strategies to promote authenticity, the ability to remain true to the phenomenon under study, while the integrity is a reflection of its criticality, or the attention paid to each and every research related decision. Furthermore, as proposed by Lincoln et al<sup>61</sup> and Miles et al,<sup>62</sup> outside of the already stated strategies, one must also discuss the *objectivity, transferability*, and *application* of the study.

**3.1.7.1 Authenticity and Credibility** First and foremost, the credibility of a study must be directly related to its purpose, or what it is trying to achieve. The purpose of this study was to explore the experiences of mothers who have breastfed or attempted to breastfeed a child with tongue-tie for any period of time. Therefore, promoting authenticity required that participants had the freedom to speak, participants' voices were heard, and participants' perceptions were accurately represented.<sup>55</sup>

**3.1.7.1.1 Participants Freedom to Speak** Giving participants the freedom to speak is based around the design-related decisions of the study. As mentioned earlier, purposive sampling was utilized to ensure that all the key constituencies of relevance to the subject matter are covered, and that, within each of the key criteria, some diversity is included so that the impact of the characteristic concerned can be explored.<sup>56</sup> However, it must be taken into account that many of the mothers who were interested in taking part in this study were more likely to be the mothers who had a more upsetting experience, and

therefore were the most active in seeking change for the system. Although, it should be noted that one of the mothers within the sample had a relatively short experience with the effects of tongue-tie, and her situation was not as distressing as the others. Furthermore, even though our sample is small, the experiences expressed in the focus groups are echoed daily through the online Facebook group for Tongue-tie Awareness, Education and Support NL, which is made up of over 900 members.

**3.1.7.1.2 Study Sample** The initial goal for the project was to conduct three focus group sessions, each approximately two hours in length and consisting of 6-8 participants in each session. A total of 23 mothers or potential participants made contact with the research team following advertisement of the study, and inclusion criteria questionnaires were sent to all of them. A total of 16 questionnaires were returned, and 5 participants were recruited for the first focus group and a total of 11 were recruited for the second; however, only 3 and 6 attended respectively. Those participants who were unable to attend cited family illness and difficulties with child-care as their reasons for non-attendance. Participants were welcomed to bring their children as there were no funds available for childcare stipends. Merriam<sup>51</sup> suggests somewhere between six and ten participants, preferably people who are strangers to each other, as a reasonable number for a focus group. Two focus groups were planned with participants in the greater St. John's area and the third was planned for Carbonear, to capture the rural and urban experience. All of the potential participants who made contact with the research team were from St. John's. Therefore, all of the focus groups were held within the city. After the second focus group, it was deemed that theoretical saturation had been reached. No

new themes were emerging and the data were believed sufficiently rich from the two sessions to complete the research.

**3.1.7.1.3 Participant-Driven Data Collection** Another important aspect is participant-driven data collection. A flexible topic guide is important to ensuring participant-driven data because it allows participants to tell their own stories in their own ways.<sup>55</sup>

Throughout the focus group, I would ask open ended-questions to the participants, and let them dictate the direction of the conversation. I would prompt when necessary, and did have certain questions in mind to eventually get answered, but otherwise allowed the participants to discuss aspects of their experience that they felt to be important, as to get the most accurate representation of their experience.

**3.1.7.1.4 Participants' Voices Were Heard** As the researcher, I also had to ensure that the participants' voices were heard. The goal of qualitative description is to fully capture the elements of an experience or phenomenon. As such, researchers have an ethical responsibility to ensure that the data were not superficial. Probing for clarification and depth is a qualitative strategy used to further understanding about a phenomenon of interest, which requires attention to cues that suggest a participant might have more to tell.<sup>55</sup> For example, I would make sure to come back to a participant to probe more about her experience, if another participant had interrupted during her story. Furthermore, if a participant seemed hesitant to continue with her thought process, I would re-word the question to probe for more details. Focus groups are also a useful way to ensure participants' voices are heard through facilitated discussion, as they provide a relatively

safe environment for participants because they are not singled out to respond to specific questions.<sup>55</sup> Moreover, focus group interviews diminish the role of the researcher, making the researcher simply a moderator or facilitator to the discussion that identifies the goals at the beginning of the interview and encourages/enables the participation of all members.<sup>55,63</sup> Additionally, I presented myself within the focus groups as being impartial and neutral to the situation as to not facilitate or influence responses or recollections.

**3.1.7.1.5 Accurate Transcription** The authenticity of a qualitative description study depends not only on the ability to capture participants' perceptions but also to accurately analyze and represent them as well.<sup>55</sup> The first step is accurate transcription of the focus group interview, which I ensured by multiple sessions of typing out exactly what I heard, and re-listening to the recording to ensure it was accurate. Transcription is, at best, only partial because it does not capture the nonverbal aspects of an interview, such as a mother crying during parts of her speech, which was noted during the interview.

**3.1.7.1.6 Content Analysis** Another way to enhance authenticity and credibility is through content analysis, such as ensuring data-driven coding and categorizing. Content analysis is the most common form of analysis used in qualitative description<sup>53</sup> and involves systematic reduction of data into coded units that are clustered into categories according to shared characteristics.<sup>55</sup> Therefore, to ensure authenticity, it is of utmost importance that codes emerge from the data rather than being superimposed on them.<sup>53</sup> The second analyst and myself made sure to create participant-driven codes rather than research-driven codes, as categories should not define the data, but rather, data define the

categories that are only as descriptive, or as useful, as the data within.<sup>55</sup> Critical review of coding is an on going requirement. Because data collection and analysis occur simultaneously, remaining true to the data requires critical and on-going appraisal of the relevance and fit of codes and categories.

**3.1.7.1.7 Attention to Context** Another aspect of data driven coding and categorizing is ensuring attention to context. Content analysis requires that conversations be reduced to smaller units of data and then put back together so that similarities, differences, and overall patterns emerge, which can lead to the misinterpretation or loss of what the participant truly meant. Qualitative research is about immersing oneself in a scene and trying to make sense of it.<sup>64</sup> As with this study, I had to listen and observe the participant's words, emotions and reactions, and interpret them based on the contextual situations, pre-dispositions, societal constructs and emotions that were also at play. For example, the participants utilized sarcasm frequently within their conversations, an element that becomes invisible in the transcripts. However, noting the tone and context of the discussions in the focus group, allowed a more authentic interpretation of the meanings behind the words of the participants.

Context could not be accurately assessed without the thick description that accompanies it. Qualitative research is described as being "richly descriptive",<sup>51</sup> where additional descriptions of the context, the participants involved, and the activities of interest are included.<sup>51</sup> This detail is used to give the reader a greater understanding of the themes, relationships and experiences that have been established. With regards to this study, I

gained rich, valuable data from the participants through their detailed and emotional accounts of their experiences, adding to the data the context, reactions and their participant demographics.

**3.1.7.2 Criticality and Integrity** Criticality in a qualitative study is a reflection of the critical appraisal applied to every research decision and is a key aspect of a study's overall integrity.<sup>60</sup> In this current study, the majority of these decisions related to the authenticity of the data that have already been discussed above. However, other measures that promoted the overall integrity of the study included consistent reflection on potential sources of bias, specifically on the assumptions of the researcher(s), interpretation of reporting, and peer examination or review.<sup>55</sup>

**3.1.7.2.1 Assumptions of the Researcher(s)** A crucial component of any qualitative study is the expression of any biases or assumptions of the researcher(s). This type of research is unique in that the researcher is the primary instrument of data collection and analysis. It is with this in mind that as the primary researcher in this study I wish to make note of my personal perspective on the phenomenon being studied. I am a graduate student who has never had children, and therefore never breastfed or attempted to breastfeed. However, I come from a Biochemistry Nutrition background, where breastfeeding was a highly discussed and researched topic in terms of its nutritional make-up and its health benefits. Furthermore, I come from a family where breastfeeding is the norm, and was breastfed myself, and grew up believing that I would breastfeed if and when the time arrived.

At the beginning of the project, I did have expectations for the outcomes of the study as I was a member of the two community groups: Tongue Tied NL Awareness, Education & Support and Breastfeeding Support- NL and had seen numerous postings regarding tongue-tie, breastfeeding, and issues with the healthcare system surrounding these topics. Therefore, I expected to hear stories of frustration in terms of the experience of breastfeeding a child with tongue-tie. I also expected to hear that there was a general lack of support from the healthcare system with regards to having a child with tongue-tie. Furthermore, I expected to hear that having a tongue-tie release improved feeding practices. In an effort to minimize bias throughout the data collection process, I did not deviate from the set focus group questions and prompts, and I did not offer any personal thoughts on the subject matter during the focus group.

I am a member of the Breastfeeding Research Working Group, and was employed as a research assistant to help organize and run the Ankyloglossia and Child Nutrition Research Planning Workshop and Public Engagement Forum in September 2016. Through this event I gained a large amount of information on tongue-tie, and child feeding itself, along with hearing more first hand accounts of issues with tongue-tie assessment, treatment and management. Furthermore, I also presented preliminary results from this research at FemFest 2016, which was described as a “women-centered community festival; highlighting the experiences of all women, including trans\*, two-spirited, intersex and cis, all folks who experience gendered oppression, including non-binary and gender non-conforming people, and all those who identify as women for the purpose of political organizing”.<sup>65</sup> I gave a presentation on tongue-tie and child feeding,



the issues that are related to assessment, treatment and management using the mother's experiences, and also relating her results to the issues of women in the healthcare system, in terms of pain management, medicalization, and the lack of support for the breastfeeding relationship. As both these events occurred post data collection, but during data analysis, I must self-reflect on how my new knowledge and experiences may have altered my understanding and perception of the collected data, and how that affected my data analysis.

**3.1.7.2.2 Interpretation and reporting** The interpretation and reporting of material are especially vulnerable to the introduction of bias. As a researcher, to enhance criticality and integrity we avoid this by reporting all evidence that is collected, even if it does not fit our theories.<sup>66</sup> I was keen to make this apparent within my results and discussion, as I report the cases that align with an argument, but also balance with the ones that do not.

**3.1.7.2.3 Peer Examination or Review** Another way to ensure criticality and integrity is through peer examination or review — a process whereby a researcher would “ask a colleague to scan some of the raw data and assess whether the findings are plausible based on the data”.<sup>51</sup> The committee members for this study included experts in quantitative and qualitative research along with breastfeeding and tongue-tie. Furthermore, our committee also consulted an expert in qualitative research to provide significant guidance and support to our methodology section. The committee met regularly to guarantee thorough data collection and analysis, and to assess the findings as to ensure the credibility and validity of the research. Furthermore, the themes were

discussed at length with the committee to ensure they flowed logically from the transcripts and that to discuss alternate interpretations. I feel that the use of rich, direct quotations, as well as full disclosure of categorical findings, enhance my confidence in the emergent themes and will allow future readers to judge the credibility and integrity of this study as a whole.

**3.1.7.3 Objectivity** Objectivity is conceptualized as “relative neutrality and reasonable freedom from researcher bias”<sup>54</sup> and can be addressed by describing the study’s methods and procedures in explicit detail, sharing the sequence of data collection, analysis, and presentation methods to create an audit trail, being aware of and reporting personal assumptions and potential bias, and retaining study data and making it available to collaborators for evaluation.<sup>57</sup> This research study aimed to follow all of these steps, as the study’s procedures and methodology has been clearly outlined along with personal assumptions and biases being reported within this chapter, and the study data will be made available to collaborators for evaluation and future projects.

**3.1.7.4 Transferability** Transferability speaks to whether the findings of your study have larger impact and application to other settings or studies.<sup>57</sup> To aid in transferability, I made sure to describe the characteristics of the participants fully so that comparisons with other groups may be made, and that potential threats to transferability from our sample were stated. Also, I made sure to present only the findings that are congruent with theory in chapter 4 (Results), and have suggested ways that findings from my study could be

tested further by other researchers in chapter 6 (Strengths, Limitations and Future Research Recommendations).

**3.1.7.5 Application** Application speaks to the utilization, application, or action orientation of the data.<sup>54,62</sup> To address application, findings from this qualitative description study will be made accessible to potential consumers of information through publication of such things as a manuscripts and summary reports. Furthermore, the preliminary results have already been presented three times at poster presentations. In addition, the hope is that these study findings may stimulate further research, promote policy discussions, and suggest actual changes to our healthcare and education system, as outlined in the recommendations in chapter 6.

**3.1.8 Ethical Considerations** Ethics approval was obtained from the Health Research Ethics Authority (HREA) in January 2016 (Appendix E). All members of the research team were informed about their responsibility of privacy protection and signed an oath of confidentiality. I discussed the consent form with the focus group participants whom were asked to provide consent prior to conducting the focus group (Appendix F). Participants were given time for questions, and it was reiterated to them that they were free to leave the study at any time. Participants were assured that their information would be kept confidential and that they would not be identified in the results of this study. The risks associated with the study were minimal. However, the interview had the possibility of bringing up topics that could be distressing for participants, therefore a list of counseling services and resources was provided (Appendix G). There may also have

been economic/social inconveniences such as having to drive to the focus group, along with the social inconvenience of taking time out of their day to complete the focus group.

## **Chapter 4.0 Results**

The purpose of this study was to explore the experiences of mothers who breastfed or attempted to breastfeed a child with tongue-tie. A total of nine women participated in two focus groups that took place in February 2016. The participants were asked to share both their thoughts and experiences regarding child feeding and tongue-tie, and their related experience with the healthcare system. This chapter provides information on participant characteristics and the results of the analysis.

The transcripts from each focus group were transcribed and analyzed. The participants' perception of their experience revolved around their emotional well-being, strain in relationships, lack of priority for the breastfeeding relationship, lack of systemic support for tongue-tie, the mothers' perception of the child's experience pre and post release and the breastfeeding relationship. Emotional well-being is centered on how the experience of having a child with tongue-tie affected the participants' emotional well-being. Strain in relationships looks at how the experience of having a child with tongue-tie affected the relationships in the participants' lives. Lack of priority for the breastfeeding relationship examines how the healthcare system and society were not supportive in maintaining the participants' breastfeeding relationship. Lack of systemic support for tongue-tie illustrates the perceived lack of available knowledge and care regarding tongue-tie, and how the participants envision change for the future. The mothers' perception of the child's experience pre and post-release describes the experiences of the participants' children before and after their release and the release procedure itself. Finally, the

breastfeeding relationship demonstrates the lengths the participants went through to maintain their breastfeeding relationship, and how some participants began to question their own beliefs.

*All names within the quotes from the focus groups have been changed to pseudonyms.*

#### **4.1 Emotional Well-being**

The main theme that emerged from analysis of the participants' perception of their experience was the effect it had on their emotional well-being. The stories of the participants were intertwined with the emotion and the effect that their experience of having a child with tongue-tie had on their emotional well-being, even when it was not explicitly stated. The majority of the stories from the participants were touched with very similar experiences; such as the physical and emotional pain of having a child with tongue-tie, the overall dismissal by the healthcare system and by friends and family, and a sense of obsession with their child's tongue-tie and eating habits. However, there was also evidence of resiliency throughout their experiences along with relief once their child received a "proper" tongue-tie release.

**4.1.1 Physical Pain** The concept of pain was discussed thoroughly during both focus groups. Almost all of the participants commented on the incredible amount of pain that came from trying to breastfeed a child with tongue-tie. When asked to describe their experience of feeding their child, one participant simply remarked: "Excruciating pain."

Another participant, who found out only after her second child that both her children had been tongue-tied described,

Like I didn't want to latch my baby to my breast because I knew it would be excruciatingly painful. Toe-curling, foot stamping, like I utilized my labor breathing for about 2 months. It was very painful and everyone kept telling me that the latch looked perfect, the latch was great, and so I tried all the different positions, and all the different pillows, and all the different chairs and all the different everything... and the "latch was good" but it was so painful. Both babies.

Beyond the pain that came with trying to breastfeed their children, many participants talked about the physical damage that was being caused to their bodies. One of the participants spoke candidly about the gouges she endured to her nipples,

I had a lot of pain, and like really, like, I called them like gouges, like huge gouge sores on my nipples that were like down to the tissue. When I showed them to the lactation consultation she was like "I can't believe you're still breastfeeding..." because every time she would latch on, like tears would stream down my face, and ah...it was very painful.

As the participants shared their experiences with pain while trying to breastfeed, it was evident that this physical pain had also been contributing to distress in their emotional well-being.

**4.1.2 Emotional Pain and Distress** The concept of pain was also evident in terms of the negative effects it was having on the emotional well-being of the participants. The common experience for most of the participants was an overwhelming desperation to figure out what was going on with their child, while also feeling isolated and unsure of what to do next. One participant exclaimed,

I think that like for me, the biggest thing is that, like you become so desperate. I don't think I can stress enough how desperate I was when things, like really got bad. I think it was like on a weekend too, so I was like, there's no breastfeeding clinics available, my nipples were like beyond painful, I was like holding her hand every time she latched on so that I could like, not grab and scream at something, and luckily I had friends who were family doctors - not my family doctor, but she sent in a prescription and I went and picked it up that day, and like that gave me hope that I could make it to the next day. But you have to feed your baby, so you do become desperate for any support. I think that night I wrote La leche league, I wrote anybody that I knew on Facebook that had an experience, I talked to her, I talked to my... I talked to anybody that would listen because you're so desperate at that point.

Another point brought up by the participants was the differing opinions regarding tongue-tie that they received from their healthcare professionals, such as its diagnosis and treatment, leaving many of the participants frustrated and confused. One participant said,

I think the most frustrating part that I found is that everybody has such differing opinions on it, and you're kind of, if you're a new mom, which I was at the time,



you're kinda like left on your own to make the decision as to what's the best to do.

As the participants told their stories, one thing was very clear: they were all just trying to do what was best for their child. All of these parents had planned to breastfeed pre-natally, as they believed breast would be “best” for their child. For some, the experience of trying to breastfeed their child with tongue-tie had led to a sense of failure. One participant, who came from a family of breastfeeding advocates exclaimed,

I just felt like I sucked... like it took me over 2 years to get pregnant, I was on fertility medication, all that crap so I felt like... I couldn't even get pregnant to begin with, then when I have this baby, cause I'm like, very type A, I'm... I'm very goal orientated, things work when you work hard enough, and then if I read one more time that, and I don't mean to be critical because I know the breastfeeding help groups are really useful, but if I read one more time “If you try hard enough, it's going to work” I was going to lose my mind... cause that was... you already feel like you suck at it, and then to read that “Oh, you're just not trying hard enough” I'm like, “how much more can you try?”

Participants reported that these experiences caused considerable stress. The participants explained that trying to feed their child, take care of their home and family, and also themselves was exhausting. One participant remarked about her dedication to trying to breastfeed...

Well I mean, I was, I was literally... that was all I did for 24 hours a day for 9 weeks straight, before I finally said “I can’t... I’m giving this child the bottle so somebody else can do it while I at least pump” cause I would breastfeed, top up, or supplement, pump, repeat.

Another mother when asked how the tongue-tie had affected her personally, remarked, I felt like I couldn’t enjoy my baby, umm... because she was constantly, constantly spitting up, I can’t stress enough how much came out of this child... umm, so it kinda puts a pause on your life, personally, because I can’t, I can’t get groceries because my child vomits, I can’t leave my house because if I do she’s going to be covered in puke in 20 minutes so it sort of, in my situation, the stress was huge. And it just put a pause on my...our life, personally... I couldn’t do anything at all.

Another participant then piped in to say “You’re just surviving, at this point right now it is literally just surviving.” As the conversation continued, and each participant gave the details of her experience, it became clear that many believed that they had suffered emotional damage from the experience of trying to breastfeed their child with tongue-tie. One participant expressed,

I think, even like, my mother and my partner’s mother, I’m sure they thought that I was crazy because I wanted to keep breastfeeding...they were like “Why do you want to keep doing this?” and I was just like “because I know it can improve or something out there that can fix this... and...I just...you know, until I went to

public health and the breastfeeding clinic and everything after I had it revised, like I felt like, up until that point, nobody really took me seriously, or, or, even, my mental health or anything. Like I just felt like, it was so emotionally damaging to me.

Another participant added, “[...] I can’t imagine having a child with a tongue-tie and also suffering from something like post-partum depression, I feel like that is a lethal combination...” While the other participants around the table agreed.

#### **4.1.3 Guilt** A second topic surrounding the mothers’ emotional well-being was guilt.

Many of the participants felt guilt towards what their child had endured, and put blame on themselves for not being able to “breastfeed properly”. For example, one participant said, “[...] I feel like I don’t even know if I would be able to wean him myself just because of all the trouble we had, because I feel so guilty...” Another participant illustrated a similar feeling. After having breastfeeding difficulties with her first child, she fears not being able to properly breastfeed her second child, both of whom were tongue-tied:

But, as hard as it is, and as difficult as it is, it is, I don’t, I find myself waiting for Samantha to grow more, just more, eat... eat more so that I can go and be a person again, I don’t want to work out because I’m afraid that I’ll lose my milk and I don’t wanna restrict my calories because I’m afraid I’ll lose my milk, I’m deathly afraid of losing my milk again, I don’t even want to have sex because I don’t want to get pregnant and I don’t wanna go on hormone pills, and I don’t

wanna have anything in me that might take my milk because, I don't wanna steal from her, what was stolen from James and it's not fair

A participant of two children with tongue-tie who is still dealing with the guilt from her experience, added:

And I have, a lot of regret for not knowing that he was tied and the pain that he went through... for months... and learning to eat and you know, everybody just telling me "He just needs to cry it out" and I just remember sitting there one night and going "I don't want him to cry because he needs me and if I don't sleep for a month and I'm a zombie and I need to call someone to help me, that's fine, but this poor little kid needs me and I just cant leave him crying" ... all the regret I have for listening to other people, and telling me that it's normal, babies cry... it's not normal, it's not.

Furthermore, many of the participants expressed guilt for the emotions and thoughts they had, as they tried to figure out what was going on with their child. They voiced that they wished there had been a better system in place to help them cope. One mother described what she wished had been in place when she was going through her experience:

So, the mom and baby come back like, a week, a day later, three days later, a week later, two weeks later, like and a counselor be made available because there's so many guilty feelings and frustration, and you feel like throwing your baby against the wall, and then you feel guilty for wanting to throw your baby against the wall...and like, I feel like there needs to be support throughout the

whole process, and if you really wanna improve breastfeeding rates, then... there has to be pre, during and post revision care, mental and physical.

An additional source of guilt for the participants was the child's tongue-tie release itself, and the associated stretches that parents are encouraged to do after the procedure. The main risk of a frenotomy is that the mouth heals so quickly that it may prematurely reattach at either the tongue site or the lip site, which can cause a new limitation in mobility and the persistence or return of symptoms. Some healthcare providers suggest after the child's tongue-tie release to do daily stretches of the upper lip and the tongue (depending on where the tie was removed) to ensure the wound is healing properly and not closing prematurely. One participant discussed the release experience as "I was totally freaked out by the fact they were actually going to cut his tongue or his lip... and my husband had to actually help \*Local Dentist\* hold him, I had to like turn around and cry, and I sobbed." Another participant recalling her experience with frenotomy added, "Yeah I... she was on my lap, and yeah, we had to hold her, yeah... she was... yeah, it was... that was traumatic..."

However, not all the participants expressed the same distress with the frenotomy. Many exclaimed that it's such a small procedure, and as the baby is so tiny, it really was "not a big deal". However, they all agreed that the stretches they were encouraged to do after the procedure were the worst part of the experience. One participant stated that, "And I mean, I would hold him down for the procedure 10 times, over doing those stretches

again”. Another participant articulated the same guilt, recalling a conversation she had with her partner:

You know he couldn’t even stay in the room when I did the stretches for 3 weeks after, he was like...he couldn’t watch it, he’s like ”I don’t have that strength” and that was it. But, I mean, so, it took a month, it really had to, like he had to apologize to me after, he was like “I’m sorry” he’s like “I just can’t do it” and I had to forgive myself for doing it cause you know, the stretches are the worst part.

**4.1.4 Dismissal** Dismissal throughout the experience of trying to breastfeed a child with tongue-tie was something that had a profound effect on the emotional well-being of the participants. The experience of feeling dismissed by the healthcare system was common-whether it was looking for answers into why their child is having feeding issues, weight gain issues, or even when the participant was trying to get their child’s tongue-tie released, they believed that their voices were often not heard. One participant’s quote expresses this clearly:

I was really upset, really, really upset at the, all the public, I mean all the medical professionals, I was like “how, how many times do I need to ask for help?” and be told “you’re fine”, and then “I’m not making it up, I’m not crazy, this is actually something happening, and my babies symptoms are real, and my symptoms are real, and... it really hurts! This isn’t normal!”

Most of the participants reported expressing their issues to healthcare professionals about how difficult it was to breastfeed, but felt that many of their concerns were dismissed.

One participant expressed that, “People kept telling me that my nipple was really big and the babies mouth was small, like for two months?” Another participant continued the conversation by saying that: “I took her in to see the lactation consultant, and she said “she’s a dainty eater”. “She’s just a messy, dainty eater” and I said... I really don’t think that that’s the issue; I think there’s something wrong with her.” Many of the participants related to this, after having heard similar things from their own healthcare providers. Even outside of the generic hospital experience, issues were still rampant. One participant recalled an upsetting conversation with her mid-wife, “My mid-wife told me that “it’s just normal, babies just cry, it’s normal...” You know... “It’s supposed to hurt for the first little bit, that’s normal””

Many of the participants discovered their child had a tongue-tie through their own investigation, and began to search for answers and treatment for their issue. However many were met with a sense of resistance to treat. One participant said, “Yeah! I feel like the healthcare system here is like “we will fix it at last resort”, but it’s a very non-invasive procedure, I mean if that has the possibility to help...” Another participant expressed:

And I just felt like there was a lot of resistance I mean like... “Wait it out a little bit”... “I wouldn’t get it done yet” but like, “Why?”...It’s such a minimal procedure that can potentially save a child from being diagnosed from a failure to thrive or see the obscenity.

She continued to tell her story about trying to get a tongue-tie release for her child at the local dentist “I felt like unless you had, I felt like I was being interviewed... They were asking me about the... the dentist was asking me about the symptoms, like “Well, do you have this? ... Do you have this?” So, unless they had...” She continued...

“I felt like I was being pushed into a corner like unless you have every single one of them...”

Moreover, a common discussion point was the general fear of actually seeking help for their child’s tongue-tie. Many participants were afraid that their doctor would think they were being an “Internet Mommy” a term I had not heard of until the focus groups. One participant recalled:

Like there is some lag in, in family practice in terms of all the latest recommendations and everything. I know like my family doctor, and I do have a really good relationship with him, but, Health Canada came out with new recommendations for starting solids and everything and he had no idea what baby-led weaning was, so I, you know, he... and I mean he was supportive but there’s some things I never even discussed with him cause I’m like, I don’t want to seem like one of those moms whose “Internet Moming”, you know?

Another participant responded with “Yes! But, if you don’t “Internet Mom”, then...” implying that sometimes that is the only resort for a parent. Similarly, in the other focus group a participant had a common thought “But I feel like Moms are getting a bad reputation that they’re self-diagnosing, but if you don’t do it, you might not get anyone to



do it.” Furthermore, as tongue-tie has grown to be such a hot topic in child nutrition, many participants were afraid that their issues would not be listened to, expressed by one participant as, “And, my fear is especially because so many people are suggesting it and everything that it just might become you know, it might fall on deaf ears, just because, I don’t know...”

For some of the participants, their issues occurred when tongue-tie was not well-known, but were aware that tongue-tie was now becoming a common term, especially within the breastfeeding community. One participant mentioned: “I feel like since I found out she had, I feel like everybody knows somebody in the last 6 months has been born with a tongue or lip tie, like it’s, and I think that’s why my doctor is like... “everyone’s been diagnosed, it’s over diagnosed” which one participant rebutted with “Large number of diagnosis doesn’t equal over diagnosis” - to which the group vocally agreed, she continued: “it means more accurate diagnosing... or MCP is going to stop covering it...”.

Dismissal was also felt from the family and friends of the participants, once again taking a toll on their emotional well-being. One participant described the experience as, “Mhmm... Yeah, you just feel alone, you feel like nobody understands, especially when everyone was saying “the latch is fine!” ha...” Another participant brought up an interesting point:

It’s almost like the stigma with depression or fibromyalgia, things like that, silent things that no one else can see and feel, nobody else knows, but you just know, instinctually that there’s something wrong with you, and there’s something wrong

with your child, but ultimately, you know it's, it's for me, it felt like ah... like they let me down. You know, they didn't believe me, they wouldn't listen to me, they put me off as if I was faking it or pretending or they fluffed it off as "Well, just give her a bottle, you know, give her a bottle" and I was like... you don't understand, like, I know I work, I know there's something wrong.

Being a parent is never a straightforward road, and can be quite difficult even with a child that has no "issues": one participant described this quite eloquently, because at the end of the day, a parent really does know best:

But, I think that it's important to kind of, you have to put it in the right context, like what is being a first time mom and figuring out the breastfeeding, and babies that can lots of time be fussy in different ways, and what is something that needs to be changed in order to help this baby feed. And I think that, people often just dismiss Mom's concerns that they're just regular things, you know, this woman, the LC at that point, when I started to cry she was like "you're not getting enough sleep... you're exhausted...you're overwhelmed... it's normal.... Your baby..." you know... we're all those things, and everyone is going to be those things, and breastfeeding is not for the faint of heart, it is really not, it's a commitment like you've never experienced before, your body is not your own, you know, your baby needs you to survive, you know, you can't just go to the store, can't go to a movie, can't do those things unless your baby is with you and um, you know having a support system is very important but in the middle of the night it's you

and your baby. And you can have a good husband or grandmother or anyone you want, it's you and your baby, and you know if your baby is not right.

**4.1.5 Obsession** After reviewing the transcripts of the two focus groups, some of the participants stated, and others alluded, to the idea that they had become obsessed with their child's tongue-tie, and eating habits, which undoubtedly affected their emotional well-being. One participant recalls:

You know, you're obsessed with this... and not a whole lot of people understand it and my partner has the completely different personality, and I mean, obviously he has no idea about, you know, what it's like to physically breastfeed, you know, so he was very supportive, but I mean, until, and I, and I didn't have anyone, and I didn't have anyone who had had the procedure done until I talked to a la leche league leader, and I went to a meeting, and she was like "You need to get this done"

Some of the participants also mentioned how concerned they were with their child's eating habits, such as one participant recalling:

From what I understand, I mean I only have one baby, but breastfeeding mothers in general I think can become very paranoid about the supply. I was extremely paranoid, I used to rip him out of others peoples arms if he started to cry "He's hungry". It was literally only maybe once he was established on solids for a good 4 months, maybe, he was 13 months, around 10 or 11 months where I actually stopped being paranoid that he was hungry all the time. And I mean he was eating

a lot of solids at that point, but I would... I used to follow people around, and he would be in other peoples arms and I'd be like "Is he hungry?" I think he wants to feed, he's really hungry...".

Another interesting finding was even though all of the participants had their child's tongue or lip tie released, with all seeing improvements since said release-many of them still spoke of having (or going to have) their child's tongue or lip tie reassessed to see if it still needed to be released more. One participant noted that:

Yeah, there's somewhere in Ottawa, I'm still going to get them to look at both of them because I think if I had gone back to them... Yeah. The older one hasn't been revised and I think she needs to be...well her tongue was revised a little bit, but I think it needs to be done again...

Another participant also echoed these thoughts by saying:

So, they did his lip and his tongue and it, it improved significantly, almost immediately. Um... and it was a hard recovery, that week was really hard for pain for the baby, and worry for mom. Ah, but it, it worked, but it, I did the exercises, but seemed to come back, and we had it done the second time with a Dentist in St. Johns, and that seemed to rectify it. So I suppose...

Moreover, the participants spoke to the fact that even if the release "seemed to have worked", after a few weeks the tie may return if the release had not gone deep enough. Therefore, many of the participants were worried about this occurring. One participant,

who had significant improvement from the release, still worries about possible future issues:

But then when you baby has the revision done, but then you're waiting for them to get old enough to try food, because then you're afraid that there's other issues... am I going to far ahead? So now, like we are waiting for him to start saying words, and waiting for him to start eating solid foods, and thank goodness he's fine, he can say lots of things, but you know, we are still waiting to see if he has a lisp or a stutter or you know. All those worries are still there until you figure it out, right?

**4.1.6 Resiliency** In terms of the participants' emotional well-being, resiliency was quite evident. As the participants detailed some of the horrible experiences they had endured, they also spoke of their determination to keep going, as seen by one participant saying:

It made me more determined in one way, I'm just like, "Oh god... like he did suffer for a couple months because I was so adamant to keep going" because I thought that I could do what I could to improve, like, I used to wake up in the middle of the night and I would be doing research online... I started on the herbal supplements before we ended up getting the revision, the Blessed Thistle and Fenugreek, because he had depleted my supply so much because he couldn't sufficiently...

Another participant exclaimed, “So, I refused to give up breastfeeding because in my head I was breastfeeding until they wanted to quit breastfeeding right? So there was nothing going to stop that.”

Many of the participants also discussed self-advocacy, with respect to getting proper assessment, treatment, and defending their breastfeeding relationship. One participant remembers:

I felt like I was constantly on the defense, like defending my decision to keep going, even though we were having so much trouble, so instead of people, and I mean, the general public couldn't be blamed, because who, unless you experience it, like who knows anything about a tongue-tie, but in general there's this like “Well, you know... you tried...”

The participants spoke about how they had to fight to get help for their child:

I had to beg for it, when I called my public health nurse and just sorta said, and I got in with a Lactation Consultant in St. John's and she was really good but my problems weren't going away and then I went to another Lactation Consultant in St. John's, it was one of those days my daughter was losing her mind, she wasn't latching, and the lactation consultant, and it was a busy clinic, she does have busy clinics, and she said “come to my office next week, we're going to meet for an hour” and I went for an hour every week, multiple weeks. She was great, but at that point I was a bit of a lost cause.

Another participant brought up: If the participants had not self-advocated, things may have been very different for the participants and their children:

But I, but what I also think that... imagine, like it seems like the women around the table here, you know, advocated for the child- rightly so, and did what they had to do to get things done, but imagine if you were a person who didn't have any support, who found it hard to advocate for yourself let alone your child, you know, came across these barriers that we all came across... um, just think about the impact for the child I guess and them right.

Another aspect of the resiliency of the participants was their drive, not only to self-advocate, but to become educated. The participants used their knowledge to advocate for their own children and for other parents who were going through the same struggles. Many of the participants spoke of researching and learning as much as they could on tongue-ties and how it can affect the breastfeeding relationship. As many of them had received much of their support from their peers, they were quite ready to do the same, illustrated by one participant saying, "I feel like I'm a broken record, I private message anyone who talks about it online, I have educated all of my family and friends about it, so to the point where I feel, I just find I will arm anyone who will listen to me with information."

A common idea was that many of the participants felt like they knew more about tongue-ties than their healthcare professionals. One of the first time mothers recalled:

I did have to supplement him for a little bit and then I had to advocate for myself to get put on Domperidone, I essentially had to tell my family doctor everything that I knew, because he didn't really... he's a great friend and a great doctor but I just felt like I knew more information than he did.

When I asked if the participants would recommend a release to another parent, all of them agreed that it had helped their situation, but would support a parent in whatever their decision, such as one participant saying:

I would stand behind someone 100% and help them understand the procedure and share my experience to let them know that what it has done for my children and my breastfeeding as well as their eating and sleeping, like afterwards. I would definitely recommend that if someone was having issues to have it taken care of. That said too, I would also you know, I would point it out as a suspected issue, and then tell someone how to get help to find out, but I would not diagnose someone else's kid with a tie and say "You need to go do this"... I would just say, you know, "Here's my experience, this is why, and this is how it got corrected... so maybe you need to see someone and see if that's your case"...

**4.1.7 Relief** The last common theme that affected the participants' emotional well-being was relief. Relief in the stories of the participants usually connected to the effects of a "proper" tongue-tie/ lip-tie release. When the group was asked if they felt the release improved their breastfeeding experience, one participant simply replied "Huge". I heard



wonderful stories of the experiences of the participants and their children, once their child had been properly released. One participant details her experience with the release:

So, the day after her revision, we were at my parent's house in Ontario and, she... my one year old daughter has a niece whose 1 and a half... so my one year old daughter has a niece whose a year and one half and she was walking around with a sippy cup and my daughter went over, grabbed the sippy cup, and drank, from it! Like, without choking! And without it spilling all over, and sputtering. She would always cough and cough... she was choking. So she drank from it, and she looked at me and she was like "OH", definitely... It was like... "Where have you been all my life? Sippy cup, I love you!" and she drank where she slept, she napped with her sippy cup, like, she was like fine. She could eat with a spoon, she wasn't projectile vomiting, because she wasn't eating with air, and I never had blocked ducts... after, it was so different.

Another participant, who struggled greatly with her child's reflux, recalls how the tongue-tie release affected them:

And 3 hours later she took her first nap she ever took in her life lying on her belly, she was never able to because of all the reflux she would sleep on top of me, she slept for 3 hours, which she had never done in her life. She never slept for more than 45 minutes for the first little weeks of her life, and no looking back, it's been immediate massive improvement right away.

An even “smaller” accomplishment was remembered with a smile by one of the participants, “I remember the first time I saw my son’s tongue, I cried... because I had never seen him lick his tongue-out, he couldn’t do it, you know...” It was evident that these victories for the participants were paramount to their emotional well-being.

## **4.2 Strain in Relationships**

Throughout the two focus groups, I asked the participants to discuss how the tongue-tie had affected the relationships in their lives. Many of the participants described the tongue-tie “experience” as putting a strain on the many relationships in their lives, from their own family members to their healthcare providers.

**4.2.1 Spouse** One of the first relationships described to have been affected was the one with their spouse. When asked how the tongue-tie had affected their relationship with their husband, one of the participants responded, “I think it wrecked my marriage. We’re ah...we struggle as parents, we struggle together but, I can’t, I can’t be happy because I don’t have the same bond with Jen as I do with Sam”

Many of the participants felt that they were carrying more of the burden for caring for their child with tongue-tie, seen by one participant saying:

But it makes, intimacy difficult, it makes parenting difficult, it makes your relationship difficult, and like even just this morning getting out of the house just to come here was a trial. Just, you know, it was difficult because I, Matt doesn’t

really like to be at home with Dad, and Dad doesn't really know how to do it...  
he's more of a babysitter than a caregiver because he really can't do much...

A participant replied to this with "my husband felt horrible for me", to which another participant countered, "I don't think it had much affect on my husband, I mean, I was under a lot of stress, I mean everybody was under stress but..."

Many of the participants felt that they were the only ones that could take care of their child, and their husbands were simply not up to the task. One participant recalls:

And my husband was supposed to take maternity leave, and I was supposed to go to work and I couldn't work because he couldn't eat, he would go 8 hours without a drop of food because he wouldn't take it from a bottle, and my husband was losing his mind, he didn't know what to do.

A participant who was a parent of two adds:

I work two hours a night, four times a week, and if my daughter starts crying luckily I just get in the truck and come home and I feed her back to sleep, because there's no other way to stop her from crying, that's it. So, a two hour job can take me from two to four hours depending on how long I have to come back and how much I have to do when I get back to get her to settle.

However, one of the first time mothers added a refreshing point about her and her husband's experience:

It brought me and my husband closer together actually cause there's nothing now that he hasn't seen... and experienced and heard me say... and ah, but, I'm glad that happened because, whatever I experienced I made sure that he experienced it too. If I was up at night, he was up at night. If the baby was upset then I made sure that like we were both holding him.

**4.2.2 Other Children** Another relationship that suffered strain due to their child's tongue-tie was the relationship with the other children at home. Many of the participants struggled to take care of both children, as their child with tongue-tie seemed to envelop so much of their time, and patience. One participant recalls thinking:

Do you try to get rid of or take care of the other children while you try to feed this baby and it's just so painful and then I found it affected for, you know, with my other children, you try to go and give them a hug and you're so sore, and you're so pained, and it goes on and on and on for months and months, and you're like "Okay, this has got to get better".

Another participant added sadly:

I don't mean to diminish anyone else's experience, but when there's an older kid there too that you also have to care for, it makes it another element of difficulty. My poor older daughter watched "Planes, Fire and Rescue" every single day for a month because this kid was crying and screaming. I mean there's two of them around... it's difficult.

Finally, another participant recalled her experience for the group:

I think what I found tough was that I, I felt that I wasn't giving to my older child the attention that he needed, and he was really struggling with the fact that Mommy is breastfeeding another baby, and there's a lot of changes at the time, and he went through a really difficult time. He would say "that's my milk" ... and here I had a baby who needed me, and we would like bar ourselves in, like baby central room with all of our things and my attention could only be on the baby, so I let him...try and latch on, my three year old, and he couldn't do that, of course they forget very quickly how to do it when they get older, and I said "it's yucky right, it's for babies" he said "no mom, it's delicious" but he didn't ask anymore, he didn't ask to do it anymore, but he went through a really hard time because he had me all the time, and then he didn't have me hardly at all, and I had...I had a lot of guilt that I felt like I was taking away from him. And he had my husband, and he had lots of family, but I...I had to focus on my son, he needed me, he struggled.

**4.2.3 Friends and Family** The relationship with the friends and family of the participants also suffered strain due to the child's tongue-tie. Many of the participants discussed how their parents did not agree with the choices they had made regarding their child's tongue-tie, some parents simply not believing that it was an actual "thing", as recalled by one participant, "And then you're telling family members like this is actually a thing, and they're like "Are you sure?""

Another participant experienced a very similar situation with her parents:

My parents didn't quite so much understand why, so it ah, I think it, um, because it has some...voodoo, like what, no one really says this is the thing that you have, you go the doctor, you get a blood test, you get an x-ray, you get a whatever and someone says "here you go, the readout says that you have this..." because there's an element of a whim and a prayer involved. If someone doesn't, I don't want to say believe you, but if someone doesn't understand the wealth of information that the parents amass before they decide to get this surgery for their kid, it can be a strain on that relationship.

Many of the participants had similar experiences with their friends. The participants recalled trying to get their friends to understand what a tongue-tie was, the release process and then defending their decision to get the release, such as one participant recalling:

So yeah, I have friends that I know, friends that don't have children that I know... question our decision, especially, to travel. My husband was off from parental leave and he had to back early because we had to use up the remainder of the money we had saved for him. He had to go back to work 2 months earlier than he attempted to, because we used that pot of money to go to Ottawa. So we have friends that think that we are crazy to do that, and I think that, I mean...she's 9 months old now so the strain is, it's somewhat improving but it does depend on the opinion of the person you're considering. If they agree with you or believe you know what's best for your child, that you're doing it from the right

perspective, then, possibly strengthening or not changing the relationship. But if they don't agree with you, it can be difficult to articulate to somebody who hasn't experienced it, why it's so... why you are so desperate to get something done immediately.

**4.2.4 Healthcare Providers** Another relationship that became strained from having a child with tongue-tie was with the healthcare providers of the participants. When I asked: "How do you think dealing with your child's tongue-tie affected you personally?" anticipating hearing about the mother's experience, the first response from one of the participants was "Don't trust the system. Don't trust the doctors" indicating the level of distrust she had for the medical system. One of the commonly discussed healthcare provider relationships that had been affected was with the participant's family doctor. One participant recollects:

I found that my family doctor was not supportive of it at all, I went to see her probably when she was, pretty young and had told her and had told her that she had has the lip and tongue-tie revision done and she was like "that's being diagnosed way too much, I would never have sent you a referral there" and when I went back to see her when I was having the supply issues she was like "I'm not sending you back to \*Dentist in St. John's, if you want to get a referral from somebody else you can, but I'm not sending you back there", and just gave me a prescription for Domperidone.

Another participant added, “But it... it sucks, and you get doctors who won’t believe... My family doctor didn’t believe. My family doctor told me it was all in my head...”

The participants were visibly upset from the experiences they had with their family doctors. Many of them were frustrated with the idea that as a participant they had to educate their own doctor on their child’s issues. One participant recalls discussing release options with her family doctor:

I don’t know if it’s money-making, that people think it’s a money-grab, or if, you know, providers just don’t have a clue, but, I had a dispute with my family doctor, I refuse to go back to see him, I’m actually in the process of finding a new doctor. Because, he didn’t believe me, and I felt like I was educating him and that’s wrong. Like, I shouldn’t have to educate him, a man who’s gone to school for X amount of years and prides himself on being a family doctor for women, like that’s, that’s ridiculous.

Unfortunately, it was not just the relationship with family doctors that had been affected. The participants had begun to distrust other healthcare providers, and questioned healthcare accountability. During one of the focus groups, the participants got on the topic of release care within NL, and as a group discussed the system that was in place:

Laura: And you had no choice but to go to THAT doctor because there’s nobody else who does it

Joan: He says he “went deep”, that doesn’t mean he did



Rita: Who knows if anyone is keeping record

Laura: Yeah... I don't know if that's something that's really recorded...

Eileen: Diagnosed, versus revised, versus... is he keeping record, does anybody know what he does?

Rita: I don't know... who... but whose... like, is there anybody, is there an overseer, or "proceduralist"?

Eileen: Is he accountable to anybody?

Laura: But there's no accountability? I don't know if there's accountability, somebody should be...

Joan: I don't know if there's any standard procedure...

#### **4.3 Lack of Priority for the Breastfeeding Relationship**

Another prominent theme that evolved from the transcripts was the lack of priority for the breastfeeding relationship. Many of the issues that the participants encountered could have been avoided or improved if more emphasis had been on preserving the breastfeeding relationship.

**4.3.1 Healthcare system** As the participants discussed their experiences with the healthcare system, it became evident the mixed messages they had been given. Even though many of the participants had been told that breastfeeding was the best thing for their child from their healthcare providers, when the participant had issues breastfeeding, many participants were told to “go to the bottle”. One participant recalls, “The doctor was like, “Well, if you’re still having problems, there’s always the bottle””

The group of participants basically responded in unison “Just give him a bottle”, a saying all of them were familiar with. All of the participants in the two focus groups had attempted to breastfeed their child, however the healthcare system that had instilled in them the benefits of breast milk was not there to support them on their breastfeeding journey. A participant tells the group her experience as a first time mother trying to breastfeed:

When I had my first child, and he lost a lot of weight in the beginning and it was taking longer for my milk to come in, they threatened formula. Like “If he doesn’t gain weight, or if he loses this much, we’re going to have to supplement” and I said “No”. But, he didn’t have issues with latching on, it was just I was a first time Mom, he was a big baby, he had a lot of fluid, he lost a lot of weight, and from that point on I just had him attached to me, I didn’t let them bring him out of the room, you know... I did some reading, you know all the things I had to do.

Beyond the benefits of the milk’s nutrition, the participants felt that the physical relationship of breastfeeding: such as the bonding, and the experience, was not being

recognized by their healthcare providers. One participant gives her view on the issues of breastfeeding in NL, and why mothers end up quitting:

I had a huge conversation with \*Lactation Consultant in St. John's about this one day and we were saying that its probably been going on forever but people just switched, breastfeeding wasn't so, such a... in the spotlight as needing to be done, so as soon as people had problems, people just switched, especially here in NL, we have the worst rates of breastfeeding in the country so, when people were having problems, they just switched right over! And, when I went in with supply issues to my doctor, the first thing she said was "Well, do you just want to switch to formula?" and I was like "no, that's not really the point... like... that's not why I'm here"

**4.3.2 Society** Society was also pinned as not supporting the breastfeeding relationship for these mothers. The participants discussed how not only did they have to fight to validate their experiences with a child with tongue-tie, but also fight to defend their breastfeeding relationship. One of the participants made the point that:

Breastfeeding attitudes in NL is a whole other issue... That's a whole another ball game, because...So not only are you battling against the medical professional, you feel like you're... "Ah, I have to be an advocate", but then you also have to be an advocate, just to society!

Nearly all the participants spoke to the fact that friends and family in their life pushed them to give up on their breastfeeding journey, encouraging “the bottle” at every chance.

One young mother bitterly recalls:

My family and everything, were like “You gave it a good go!” And he always took a bottle when I pumped, so my mother in law used to be like “Sure, he loves his bottle, just give him a little bit of formula” And when I was supplementing him, until I felt like we supplemented for about a month until I felt like his weight gain was going good... like, she was like “See I told you he loves it, that’s why he’s gaining all the weight”

Another mother coyly added: “What’s so important about breastfeeding anyway?” a comment she had heard many times throughout her breastfeeding journey.

#### **4.4 Lack of Systemic Support for Tongue-Tie**

Another theme that came clear from the transcripts was the overall lack of systemic support for tongue-tie. The detrimental effects from their experience were often related to this, as they spoke about the lack of pre and post tongue-tie release care, a general lack of knowledge about tongue-ties, having to endure multiple procedures, going from one healthcare professional to the next to get the best support possible, and usually ending up relying on the support they found from their peers, and the internet. The participants were also quite willing to offer up their own recommendations for the healthcare system, as to improve it for future mothers and families who are dealing with possible tongue-tie issues.

**4.4.1 Lack of Pre/Post Tongue-Tie Release Care** One of the main concerns that participants discussed during the two focus groups were the lack of pre and post tongue-tie release care they received. Many of the participants had no idea what to expect when they were getting a release done, and were not explained to what the procedure would entail. Furthermore, many of the participants were unsure of how to proceed post-release, with some participants not even told about the proper stretches that are advised for post-release recovery. One participant details her experience:

What I found was that I went for a consult, not prepared that he was gonna do it. And... I felt like he was good with the baby but not so good with me. I was a bit, ah, I asked a lot of questions, I was direct with him which I don't think he liked very much, I'm not trying to destroy a person but, he was nicer to my husband, because my husband's quiet. I didn't feel like he answered my questions and he didn't explain things to me very well, everything I learned about the stretches and the exercises I learned myself on the Internet. He could have gave me a pamphlet, that had the information, he didn't do that. And I ended up having to go back again, because it wasn't, the improvement wasn't enough and he had to do it deeper.

Another participant echoed similar sentiments, wishing that something validated had been available to her when she was dealing with her child post-release:

But having a website that's been certified and validated by health professionals in the province I think would have given me a lot more confidence. I mean I did it anyways because I was desperate, but you're going and you're putting your fingers in your kids mouth going "Jesus, I hope this video is the right video that

I'm supposed to follow" ... or that this person's opinion is the right opinion that I'm tapping into and not the 20 others that counter it. So, you have to be very optimistic or hopeful when you're reading through a Facebook group to hope that this is the best course of action, but that was truly where I found 99% of the information about what to do with a child with tongue-tie, and that makes me very... and I'm a researcher and I'm listening to myself going "What were you thinking?" ... but, you do what you gotta do!

**4.4.2 Lack of Knowledge** The participants also frequently brought up that they found there was a general lack of knowledge surrounding tongue-tie, from assessment, to diagnosis to treatment. The participants found themselves going from one healthcare professional to the next to try to attain a consistent answer. One participant recalls her experience of trying to get her problems properly addressed:

Yeah, there needs to be, the system needs to push for somebody to be trained, and you know, followed to actually get consistent diagnosis, and consistent treatment for babies who are considered to be tied. Cause, I think that's the problem, you go, you know, everyone's just putting there little "Oh yeah, no this is it"... "That's not it", and you're just between...we need to go to all the different groups, you just end up with a confused mom going: "Okay, I'm still here suffering, and... none of you really helped me" and then, you know, and then you can't, and you're questioning what the local, like \*Dentist in St. John's does, you know, and questioning "Did you fix it? Or didn't you?"

Another common point was the issue of receiving consistent lactation support, as one participant illustrates:

I used to joke around that I was the breastfeeding clinic whore, because I went to all of them. Anyone... and they would get a little be annoyed that I was going and getting different opinions, but I shouldn't be getting different opinions, they should be all trained the same way. So it shouldn't matter if I have a problem on a Thursday and there's a clinic open, I should be able to get the services I need and not have to wait until the next Tuesday, and I found that to be really stressful, I felt like I was always un-accidentally putting in competition my lactation consultants, which I never attempted to do but, it became frustrating that there was only a single person that I thought was really that helpful.

Many of the participants agreed to her statement and mentioned that they had done similar things to try and address their feeding issues. Another participant summed up the issue quite well, saying that:

I think there has to be some sort of consistency among the healthcare professionals as to the seriousness of the tongue-tie, because I mean, you know, babies shouldn't have to be hungry and mom's shouldn't have to be in pain because people are hesitant or there's no one available for that type of treatment here.

**4.4.3 Recommendations for the Healthcare System** As many of the participants had undergone such horrible experiences from the healthcare system, many of them had ideas

of how these issues could be remedied, along with necessary changes for the future. Many of the participants felt that if there had been consistency and better training between healthcare providers, and a system to care for families as they go through assessment, diagnosis, treatment and follow-up, their experience would have improved significantly. One participant suggested:

I think, I feel like, there needs to be like a centralized place where moms can go ah... pre-revision, for revision, and post-revision. There are a lot of things that moms can do to prepare for the revision, so there should be somebody who sits down with the mom, counselor, for one thing. Lactation consultant for a second thing, what can you do in the mean time while you're waiting for the revision to happen, and also somebody whose going to sit down and tell you exactly step by step what the revision is, and what to expect, all the different scenarios that might happen post-revision. And, then give you a list of phone numbers for people and services that you need to go and see post-revision, because, you know what I mean, you can get cranial-sacral therapy, and I know it's not a medically westernized thing, but this is what \*Dentist in New York recommends, he recommends people go to cranial-sacral therapy, he recommends that you try Hyland's teething tablets, he recommends that you try all these different things, massage therapy on the babies face because they have to learn new muscles, they have to be trained, and so, there should be like somebody to meet the mom and the baby before, somebody who will guide them through the revision with the dentist, who knows what they're doing for posterior tongue-ties, and all different scenarios, and then follow up care. So, the mom and baby come back like, a week,



a day later, three days later, a week later, two weeks later, like and a counselor be made available...

Another participant pointed out that there needs to be better lactation support available as well:

I think one on one support that's not in the breastfeeding clinic would have been helpful too, like I've never seen a LC one on one I've always just gone to the clinic, but it's always like, somewhat strained because you're already having... if they're...have a lip tie, like, you're having latch issues, so then you're having, I'm not shy about breastfeeding but it's still awkward to sit in a chair, in front of a whole crowd of people and try to get them to show you exactly what you're supposed to be doing, so, like a one on one consultation as soon as... that seems to be the issue.

Another participant added that the supports are possibly already available- there is just a gap in communication in connecting them to the parents:

I think there are supports here but you have to find them yourself, which is maybe part of the problem, you know, you had said there's not enough lactation consultants, so more lactation consultants would definitely be helpful, but also if the clinics that are doing tongue-ties would know to tell parents how to find those people is a gap in the system. There are support places you can go, and there are groups you can seek out to get support but you have to find them yourself so there is a gap in the communication there some how.

#### **4.5 The Mothers' Perceptions of the Child's Experience Pre and Post Tongue-tie Release**

A key theme that also emerged from the transcripts was the experience of the child, which undoubtedly played a large role in the experience of the mother. The participants all recounted stories of the issues their children were having with regards to their tongue-tie. Furthermore, the participants also discussed having the release, along with the results of the release, and the effect it had on their child's health and well-being.

**4.5.1 Pre-Release** The experiences of the participants were varied in terms of why they sought help for their child. The most common complaint was the pain they had endured while trying to breastfeed their child, one participant explains, "The first couple of weeks I would time myself: 5 minutes on each side, but like 5 seconds in I could have stopped, it was like you couldn't really explain the pain to anyone else." Other participants spoke about their child's inability to gain weight properly. One participant, whose child had been in a Pavlic harness (a brace used to keep a child's hips aligned in the joint) until almost 4 months old, recalls arguing that there was something going on with her child and no one would listen. He was described as extremely fussy, constantly breaking the latch and had leveled off her supply, however it wasn't until the harness came off that others realized how tiny her child truly was, "I feel like a child not gaining weight from 2-4 months...Someone should have escorted me, like somewhere, like there, that's a huge deal!"

Another participant, who had two children with tongue-tie, recalls how on her second child it wasn't the pain of breastfeeding that alerted her to an issue, but the amount of reflux her child was having, "She is tied as well, so at about 4 weeks she started having some very bad reflux, violent, disgusting amounts of reflux, so I had no experience this time, pain myself, it was all her"

Many of the participants only learned about their first child's tongue-tie after they were having issues with their second, as tongue-tie had only become a common term within the last few years. Once the participants received diagnosis regarding their second child, many of them had their other children checked, thinking back to some of the issues they had endured with them, and possible issues they were having now. One participant mentioned that, "My two year old who we had done in Ottawa, I brought her when I had my son done, and she... she wasn't talking - so that was the big issue we were trying to get figured out at that time."

Some of the children of the participants were not having issues breastfeeding, but it was the pain of breastfeeding that instigated the participant to have their child's tongue-tie released, such as one first time mother recalling "Like you know my son never had a problem, he gained a pound a week every time we went to the breastfeeding clinic, he was having no problems gaining weight. So he wasn't you know, the typical tongue-tie baby, he was just painful".

Some of the participants also did not have to wait very long to get their child diagnosed. Two of the participant's children were immediately diagnosed in hospital, one participant recounts, "My daughter was born in June, early June and she was diagnosed right away, I'm very lucky, as soon as she came out they were like "Holy crap, her tongue isn't moving!" so they diagnosed her within 5 minutes of her being born"

**4.5.2 The Release** All of the participants had at least one of their children released, with almost all being completed by laser, and some by cautery. However, one of the participants did share her interesting story of how her child's tongue-tie was initially dealt with:

I have an old school doctor, she thinks differently, she said that she borrowed a pair of scissors from St. Claire's when she was there to do my son's procedure, and she attempted it herself because I was desperate, and she said, that I... seeing the baby kept her up at night, and she called me in and she attempted it, and it improved it a little bit, but then we knew we had to go further with \*Dentist in St. John's so, you know finding the right doctor's important.

Getting the actual release done held different responses from the participants. Some did not seem phased by the procedure, and others were visibly upset by how it was performed. The participants discussed their experiences with the release, some recounting how their child was taken away from them and the release was completed in another room, while other participants were told to hold their child throughout the procedure, to

which one participant remarked, “That is...that to me is appalling, a mother should not have to hold her screaming child while she, no way... my daughter was put in a blanket, cuddled, brought downstairs, they did it, brought her back to me and put her on the breast”.

**4.5.3 Post-Release** During the two focus groups, the sense of relief was evident when participants spoke about the improvements they saw from their children after they had a release. Many of the participants did not have any further issues, such as one participant recounting, “After the revision we were really lucky, and we only needed one revision. And he basically gained a pound a week for two months after that.” The participants spoke of the obstacles their child had now been able to overcome, such as finally being able to latch, to sleep, and to gain weight. One participant speaks about her child’s tongue post-release, “And now it’s free flowing. She is an amazing eater, a wicked latch, she is a happy, sleeping baby... growing really good”.

For participants that spoke of their older children getting released, they also had positive accounts to share with the group, such as one participant saying:

It was, you know, for a older kid to be released, it was amazing. He now can, at 20 months knows his alphabet, he can sing songs, he learns new words everyday, he went from not talking to talking, he doesn’t swallow his food whole anymore, there’s no, like round, chunks of carrot in his poop, it’s actually like, digested food.

However, not all the participants were quite as successful with their releases. Some of them spoke about having to go back for multiple revisions to finally get the improvements they sought. One participant in the focus group explains this:

It's the conservative nature that I have an issue with, because he is approaching it from a dental perspective, which is fine, that's what you are, but from a breastfeeding perspective, two weeks is too... pardon my French... is too f\*\*\*ing long. You can't go and get a prescription and say "come back in 2 weeks", it's not, it's not in the best interest of the child or the mother who has to struggle to feed for 2 more weeks... because you feed your child every two hours, that's hundreds of feeds, it's not good enough to say come back in two weeks. So the conservative perspective, I assume, it's coming from someone who is a dentist, but it's not in anyway putting the breastfeeding relationship first and foremost, it's clearly not paramount, because there's no reason why you or any of us should have had to go for multiple revisions.

Another participant added to this by saying: "And most people had to have the second revision, and it's always blamed on the mother... "You didn't do enough exercises!"

Which refers to the post-release stretches.

Unfortunately, for one of the participants, her second release was too late to salvage her ability to breastfeed:

So, and we went back to see him and he revised it again, and he went even more "aggressively", I think someone mentioned that, you know, he finally went

another quarter of an inch or so, and within 24 hours I did feel an improvement, but unfortunately at this point, at 4 weeks past she was born there was no milk coming out at this point so we used the supplementary nursing system.

Another participant also pointed out that maybe her release was done too late into her child's development:

I, I think that he got into a habit of waking up because he was hungry in the middle of the night and I'm not all along the train of sleep is developmental or anything but like, when you're a year old and you're still waking up like 10 times at night, I feel like there might be some sort of correlation there.

Moreover, as mentioned before, many of the participants who did have successful releases and had seen improvements, were still concerned that there would be issues in the future, and that another release would be needed. This can be seen through this participant's recount:

I mean I never had any issues with his latching anyways, but he was perfect after that. The only thing that I would find, I found that afterwards was that he was like a baby with a new tongue because he didn't know how to use it, so he was like licking all over the place all the time, and drooling a lot more, but other than that, that was pretty well it for me. Now he does spit up a lot, so now I'm wondering is it back? Hence the bib...But, he's gaining [weight]...

#### **4.6 The Breastfeeding Relationship**

The final theme that emerged from the transcripts was the breastfeeding relationship. It was clear that all the participants were very determined to have a breastfeeding relationship with their child, even sometimes at the cost of their own body and sanity. Many of the participants discussed the lengths they went through to try and have a breastfeeding relationship: the pain they withstood, the pressure of being a mother and the difficulties of breastfeeding. Additionally, as the conversation continued in the focus groups, some of the participants began to question what they went through to achieve this “breastfeeding relationship” and to what end?

**4.6.1 The Fear of Failure** Many of the participants felt let down by their breastfeeding experience and had a distinct sense of disappointment. One participant, who never achieved the breastfeeding relationship she hoped to have with her child, used a supplementary nursing system for months to try and still be able to give her child her breast milk, she recounts:

I am still breastfeeding to this day but only at night, I’m back to work at 6 months as well, my husband took the other 6 month paternity leave, but, you know it was...we’ve never had the high from the breastfeeding, and I’m really sad, I don’t know if it was because the tie ... I think it was because the tongue-tie didn’t clear itself up early enough for my milk to come in so I’ve always sorta struggled with the supply issues on top of it, perhaps they’re unrelated but, it’s very unlikely that they’re un-related. And so, it just was a, I’ve never gotten the relief or the



pleasure from the breastfeeding that a lot of people had so... but I'm foolishly still at it! And still taking...not as many...but, still taking the pills.

Some of the participants spoke to the fact that they did not anticipate breastfeeding to be difficult, especially the first time mothers. They were under the impression that once you had your child, your milk would already be in, and your child would latch on, and that would be it- however, many of them did not have this experience. One participant recalls:

My son was born at 5 o'clock in the morning, and I had him, I was in the delivery room for a couple hours and then I went and had like my own semi-private room in Toronto, and I remember, I put him to the boob and I was like "Okay, time to breast feed... Why aren't you doing it? You're supposed to just get it, right?" And I thought, like... "What the heck?"

Supply issues were also discussed, some of the participant's milk took longer than expected to come in, and some participants were never able to have a stable milk supply. Many of the participants discussed taking supplements to help their supply, something that many of them had not even heard of before. One of the more extreme cases was a participant, who described her experience with supplements, "I was on about 40 plus pills a day, between Domperidone, Blessed Thistle, Fenugreek, drinking Mother's Milk tea as if it was my source of substance, like an idiot"

Other participants discussed how their child was always trying to feed, because they were never satisfied, "Because I was so used to feeding him every 20 minutes, because he was

always on me and he was never satisfied” Another participant added, “He was never able to drain the breast”.

Many of the mothers who were not on their first child were aware of what a proper latch felt like, and how good the breastfeeding relationship can be, so when they had issues with their second child, they knew something was wrong. A mother of two recalls:

And it hurt, and it felt like matches on my nipples, and I just remember thinking there’s something wrong with her, like, she should be able to eat, she couldn’t get a latch, I didn’t have that same feeling, like that light feeling when the oxytocin just kinda just pumps through you as you’re breastfeeding the first little bit, and you’re like “Woah, I’m going to fall asleep because I’m high”... I didn’t get that feeling with her, and it scared me.

It was obvious that not being able to breastfeed the way they had attempted, or when the experience was not what they expected, the participants felt let down personally, but also that they had let their child down. One of the second time mothers acknowledged the pressures that come with breastfeeding:

And I think that when you first start breastfeeding women put so much pressure on themselves... that “I’m not doing something right”, “my milk is not coming in” ... you know, “my breasts are not the right shape”, you know... “you’re not naked enough”, “you don’t, you don’t have your baby close to you enough”, “you’re doing this”, “you’re doing that”...but really, you know it’s a beautiful combination of the mother and the baby, and the babies mouth and the babies

tongue, the mother's breast, it's a combination of everything and I think that that's you know, as women, in general, we often too much pressure on ourselves, that we're doing something wrong when it's just an unfortunate thing that happens, that your baby has a little problem.

**4.6.2 The Commitment to Feeding Their Child** Even though the participants were struggling to keep their breastfeeding relationship, they were committed to feeding their child, at any cost. As mentioned before, many of these participants endured horrible pain as they tried to breastfeed their child, sometimes to the point of damage being done to their nipples, such as one participant remembering, "I had so many gouges, like you... I walked around the house naked for 2 months just to try and get things to air out so I mean, pfft, dignity left a long time ago"

This participant also recounted how if she had not had the support that she had while trying to develop a breastfeeding relationship, she would have not been able to do as much as she did:

And I know that sounds so weird because it's like, like you said, it's so small, it's like a tongue-tie... I could have gone to formula, I could have done that and it probably would have saved myself a lot of grief but, and my parents probably, my mother said numerous times, she breastfed me but she said "I would never have gone through what you're doing, but I will support you no matter what". So, if I hadn't had that, there's no way I would have pursued what I was doing.

**4.6.3 Breast is Best?** Some of the participants were questioning the time and energy they had spent trying to develop and sustain the breastfeeding relationship, and that maybe there should have been other options presented to them. One participant clearly frustrated with her experience remarked:

American Association has come out now saying “Fed is Best” and not “Breast is Best”... I wonder how much of my maternity leave I spent in appointments and just trying to make it work with my daughter, I don’t regret it, because whatever, regrets are useless, but again that idea of the relationship, how much time did I spend trying to force this breastfeeding relationship to work when... for what? You know, when I spent half my maternity leave literally at a doctor’s appointment, or physio, or cranio-sacral, or a breastfeeding clinic, probably almost every day for months

She concludes that:

I think its important to get the tongue-tie revised for a whole host of reasons, not just breastfeeding, but if it’s too the point of causing psychological damage to the Mom, I think the baby just needs to be fed. And that’s maybe not a message heard enough.

Even though some of the participants had experienced “the bottle” being pushed on them, other participants had very different experiences. Some of the participants discussed how even when there child had been losing excessive weight, and they were put on supplements to increase their milk supply, no one would suggest an alternative option,

such as formula. However, when the participants finally asked for formula, the healthcare providers would admit that they had wanted to suggest it, but couldn't. One participant recalls her experience when her milk was not coming in and her baby was losing substantial weight in the hospital:

So I asked for formula and they said "I completely agree, we should give you formula" but they're not allowed to suggest formula... they actually said "We're not allowed to suggest the "f word" unless you bring it up"... So I said, "Okay, I want the "f word", give me the effing "f word"

Another participant described the same situation, "Yeah, I had to bring it up, I was like "You're watching my child starve... and me lose my mind...but you wouldn't bring it up!" One of the participants recalled her nurse saying, "I highly suggest you use formula but I couldn't bring it up to ya." I was like "So, you're telling me that my child was colic, and probably pushed medication on me, but you won't let me get formula?"

## **Chapter 5.0 Discussion**

The following chapter discusses the main themes that emerged from the data illustrating the participants' perception of their experience and the research questions that they answered in the context of the presently available literature. The chapter is organized according to the research questions with application of the relevant literature where applicable.

### **5.1 What are mothers' experiences of feeding a child with tongue-tie and how does this experience affect emotional well-being, relationships and future feeding practices?**

The experience of feeding a child with tongue-tie varied among participants, but all established that it had a significant impact on the mothers' emotional well-being, placed strain on the relationships in their lives, challenged their expectations of having a breastfeeding relationship, and made them question their current and future feeding decisions.

One of the most significant impacts tongue-tie has on the breastfeeding experience was pain. The first type of pain that many of the participants spoke of was the physical pain of trying to breastfeed a child with tongue-tie. Participants discussed how hard it was to continue breastfeeding their child, and how when they did, it sometimes caused horrible damage; participants described the gouges they received and sometimes even the complete loss of sensation to their nipples. These findings are reflected in the literature,

such as in the work of Griffiths<sup>25</sup> who reported that as a result of this restricted tongue action, the mother may experience painful, bleeding nipples from the friction created by abnormal tongue movements. Amir et al<sup>67</sup> also reported that nipple tenderness, nipple damage, and breast pain are common symptoms experienced by participants who are breastfeeding a child with tongue-tie.

Segal et al<sup>13</sup> adds that the prevalence of nipple pain is between 60% and 80% in all-nursing mothers during the early postpartum period, however, with a normal child “this pain is transient, peaks on the third day, and resolves spontaneously within 2 weeks”. Furthermore, only 3% of mothers of normal children have intractable pain or difficulty getting their babies to latch at 6 weeks, but 25% of mothers of babies with tongue-tie have these problems.<sup>13</sup> For mothers trying to breastfeed, these statistics are not good, as for every day of maternal pain during the initial 3 weeks of breastfeeding, there is a 10% to 26% risk of cessation of breastfeeding.<sup>68</sup>

Participants spoke of their emotional pain and distress as they searched for answers and proper support with regards to: assessment, diagnosis, treatment, and follow-up care of their child’s tongue-tie. Edmunds et al<sup>17</sup> heard very similar comments in their qualitative research on tongue-tie, as the participants in that study spoke of wanting to have the breastfeeding relationship they had imagined, and also wanted more support from the healthcare system. Many of the participants in this current study ended up relying on fellow peers and Facebook support groups to get the support they needed. One such Facebook group was the Tongue-tied NL Awareness, Education and Support, which

hosts over 900 members - their slogan is “This group is for parents of tongue-tied children and adults, as well as health care providers. The purpose is to create awareness that tongue-tie and lip tie are problems that have a significant impact on health and well-being, to help educate those who are looking for information, and to support those who are in need.”<sup>69</sup>

With the participants’ desperation, also came exhaustion. The participants spent so much of their time searching for support and answers, while being stressed about their child with tongue-tie, and simultaneously dealing with the rest of their lives (e.g., family, friends, jobs) that it had nearly worn them out. Throughout the two focus groups, it was discussed how detrimental a tongue-tie could be if you were someone with other existing mental health issues, or if you did not have any source of support. The idea of postpartum depression along with tongue-tie was brought up, and was agreed to by the group as a “lethal combination”.

Furthermore, as dealing with their child’s tongue-tie became an all-consuming part of these participants’ lives, for some it developed into obsession. Many of the participants spoke to the fact they were obsessed with finding information regarding their child, sometimes staying up all night to try and find answers. Other participants recalled becoming obsessed with their child’s eating habits, being constantly worried that they were hungry. Additionally, even though not explicitly said, it was clear from the focus group that the participants were extremely attentive to their child’s tongue-tie, even after it had been released. Many of the participants spoke to the idea that they worried the



tongue-tie would re-occur, and that they plan to get it re-assessed and possibly released once again, even if they were having no current issues.

Another experience that had impacted the participants' emotional well-being was the guilt associated experience of having a child with tongue-tie. Many participants felt guilt for not being able to have the feeding relationship they hoped to have with their child, such as not being able to "breastfeed properly", not getting their milk in quick enough, or having too low of a milk supply. These situations can lead to maternal feelings of failure along with high levels of emotional distress.<sup>67</sup> Feelings of guilt were also expressed by the mothers in the study conducted by Edmunds et al.<sup>17</sup>

Many of the participants also expressed guilt in terms of the feelings of stress and resentment that they had felt towards their child. Moreover, a major source of guilt for the participants that impacted their emotional well-being was the tongue-tie release itself. Many participants felt horrible that they had put their child through the release, and felt even worse about putting their child through the recommended stretches. However, not all participants shared the same sentiments. Some of the participants were quick to say that the procedure is so "small and simple" that it really was not a big deal. This finding has not been discussed in the literature. There is only information published on mothers' perceptions of improvements in breastfeeding post-release and not with the release procedure itself.

However, the sense of resiliency resonated throughout the transcripts. The participants' ability to keep going, to keep pushing when no one would listen to their concerns was a testament to their determination to do whatever they could for their child.

The participants also promoted self-advocacy, suggesting that if they hadn't stood up for themselves, no one would have. The participants became very self-informed, amassing information that was available to them to educate regarding tongue-tie. All of the participants relied on peer support throughout their experience, sometimes relying more on their peers' knowledge rather than health care providers. Sharing experiences with others undergoing similar life events can assist individuals in coming to terms with their own experiences that will, in turn, enable them to support others,<sup>70</sup> that was evident from the focus group transcripts. Research has found that in fast-paced urban environments, and in particular those where extended family is far away, individuals may rely heavily on information from peers and the media.<sup>71</sup>

The experience of feeding a child with tongue-tie also had a significant impact on the relationships in the participants' life. Many of the participants spoke about the strains it placed on the relationship with their spouse. The spouse was commonly perceived as not seeming to understand what the participant was going through, or was simply not able to bear the same burden when it came to dealing with the issues attributed to the tongue-tie.

Even though there is no literature to depict the effects of tongue-tie and breastfeeding on the spousal relationship, there is breastfeeding literature regarding this topic. Child

feeding decisions require considerations around a number of factors, including balancing the needs of other children and the relationship with one's partner.<sup>1</sup> Breastfeeding can be seen as incompatible with sexual relations or with a partner's wish to share in the feeding of the baby.<sup>1,72</sup> It has been reported that there were mixed findings about the perspectives of partners on breastfeeding and the impact that breastfeeding had on the relationship between the woman and her partner.<sup>72,73</sup>

It also has been reported that fathers do want to be involved and to actively support and care for their partners.<sup>74,75</sup> A major role being to "protect and defend" their partner's decision to breastfeed their baby.<sup>2,75</sup> It has been found that fathers can face a dilemma in supporting their partners when they are experiencing breastfeeding difficulties- they do not want to undermine their partners efforts but at the same time wish to protect them from pain and exhaustion.<sup>74</sup> As many of the participants in the focus groups were suffering from pain and exhaustion from trying to feed their child with tongue-tie, this may have put their partners/spouses in difficult situations: they want to support their loved ones decision, and want the best for their child too, but to what end?

Another relationship that was placed under strain was the relationship between the participant and her other children. Many of the participants recalled not being able to spend as much time with their other children because of the needs of the child with tongue-tie, which undoubtedly affected the participants' emotional well-being. Furthermore, participants recalled the strain that was felt between friends and family, when they refused to listen to the participant's concerns regarding tongue-tie, or the

release treatment. Also, some participants spoke of their friends and family questioning their pursuit of breastfeeding, and pushing the idea of bottle and formula feeding on the mother. This can be very detrimental to the breastfeeding relationship, as the beliefs, attitudes and expectations of family members can strongly influence a women's breastfeeding goals as well as their breastfeeding experience with reports of myths and outdated knowledge related to breastfeeding creating barriers within families.<sup>2</sup>

Almost all of the participants in the focus groups were employed and on maternity leave while dealing with the experience of having a child with tongue-tie. It is common today to see a mother not only holding down a full-time job, but also raising a family, and dealing with the extra demands that comes from this. From the focus group transcripts, you could see the ideology of “intensive mothering” coming through. Sharon Hays,<sup>76</sup> who wrote the 1996 essay "The Cultural Contradictions of Motherhood," described "intensive mothering" as being self-consciously committed to child rearing, which includes being dedicated to your child to the point that you take much better care of your child than yourself. Throughout Hays work, she speaks to many aspects of “intensive mothering” with a few notable consistencies seen within the focus groups. Hays states that:

Public ideology of appropriate child rearing had urged mothers to stay at home with their children, thereby ostensibly maintaining consistency in women's nurturing and selfless behavior. But in reality the wall between home and world has always been structurally unstable and insufficiently high, and over the past fifty years the integrity of its construction has been increasingly threatened by the

ever-greater number of women who have climbed over it to participate in the paid labor force.

This was a reality for many of the participants in the focus groups, as they were all employed participants who had a limited amount of time for their maternity leave, or were balancing work, while dealing with the stress of having a child with tongue-tie. Hays<sup>76</sup> notes that, “Child rearing today is, more than ever before, child-centered- it follows not from what every parent knows (needs or wants) but from what every baby knows (needs or wants)”. This was also evident from the transcripts, as many of the participants discussed the lengths they put themselves through for their child, such as: severe pain, sleepless nights and endless amounts of stress. These participants were determined to provide their child with the breastfeeding relationship, as they felt this was the best for their child. Besides for issues that were not related to breastfeeding, many of the participants could have simply turned to the bottle, and alleviated much of their stress immediately. Other participants could have given the role of taking care of their fussy, crying child to their partner or another caretaker, as this also would have alleviated some of their stress. But these participants did not, their stories illustrated that they carried the majority of the burden of rearing their child. This is not uncommon, as Hays states that “Mothers’ caregiving accounts for 74 percent of the total hours spent in direct child care, and fathers’ caregiving accounts for the remaining 26 percent. Furthermore, Hays notes that mother’s: “also worry that men don’t know how to do it right, simply can’t do it right, or are unwilling to do it right”. Hays remarks that mothers take on this all consuming role of motherhood because:

Mothers understand themselves as largely responsible for the way their children turn out. The guilt, the sleepless nights, and the worry about doing it appropriately are common to many Mothers. As it turns out, nearly all the issues that they worry about follow directly from the logic of intensive child rearing.

As mentioned before, all of the participants were in the age range of 25 and older, were married or common-law, lived in St. John's and surrounding area, and were educated and relatively affluent compared to the rest of the population of NL—indicating our sample was of a higher socio-economic class, living in an urban population. These details are important to collect as it helps to identify our participants at a social level to determine the transferability of our findings to other mothers who are experiencing the same issues. Our results indicate that even mothers who would be considered privileged, educated and well off still suffered greatly due to their child's tongue-tie, and the system that was available to support them.

The experience of feeding a child with tongue-tie also affected the breastfeeding relationship for the participants. All of the participants had attempted to breastfeed their child, and were distressed by the fact that establishing this relationship had been so difficult, if they had even managed to salvage it. Many of the participants were not prepared for how difficult breastfeeding could be, but were ultimately committed to feeding their child. The participants spoke of the lengths they went to breastfeed, from enduring the pain, to supplementation, to supplementary nursing systems.

It has been reported that many women have unrealistic expectations about the breastfeeding experience.<sup>2,77</sup> However, an unintentional consequence of describing breastfeeding as “natural” is that difficulties such as latching on, cracked and painful nipples or mastitis are not spoken about, which can undoubtedly contribute to a woman’s loss of confidence in her ability to breastfeed, early cessation and even the feeling of being a failure as a mother.<sup>78,79</sup> Openly acknowledging that physical pain and vulnerability may be a part of the early breastfeeding experience for some could help to validate early experiences with breastfeeding rather than causing new parents to feel abnormal in any way or, worse yet, a failure.<sup>80</sup>

The breastfeeding relationship also shaped the participants view on feeding practices and future feeding practices. Some of the participants had begun to question whether breast is actually best, as they had spent so much time and energy on being able to breastfeed, that some of them began to wonder if it was indeed worth it. Mackean et al<sup>2</sup> point out that awareness of the benefits of breastfeeding is not sufficient on its own to support the initiation and continued duration of breastfeeding. The authors believe that there is a need for “balance between the promotion of the benefits of breastfeeding and the provision of practical information about the common challenges women experience in getting breastfeeding established”,<sup>3</sup> and that it helps if women have realistic rather than overly idealistic notions of breastfeeding.<sup>2,81</sup>

It was also discussed that some of the participants who struggled to breastfeed wished other options had been offered to them. Some of the participants recalled healthcare

workers saying they would have suggested formula, but were not allowed. There seemed to be a hierarchal system in place where healthcare workers were unable to speak their own opinions in fear of being chastised themselves, or were perhaps unsure of how to properly support a struggling breastfeeding mother. Research has shown that “the role of both policy makers and health care providers is to empower, encourage and then support people in their decisions about health; yet ultimately the choice is the individual’s”.<sup>1</sup>

The experience of having a child with tongue-tie also made the participants question how this would affect their future feeding practices. None of the participants explicitly said that they would feed one way or the other if they had another child (breastfeeding vs. bottle) but some of the participants said they would not spend as much time trying to create a breastfeeding relationship because they would already have another child to worry about. Other participants detailed how they would make sure they had the proper healthcare supports in place before their child was born, just incase their child had any issues, referring to tongue or lip ties.

**5.2 What are mothers’ experiences with the healthcare services received? Services include their experiences with any release treatments, their perceptions of the healthcare system and professional knowledge of tongue-tie, and their feelings about access to care and available supports.**

From the two focus group transcripts, it was clear that all of the participants could detail a frustrating experience with a healthcare provider with regards to having a child with tongue-tie. Their experience with the healthcare system not only affected their emotional



well-being but also opened their eyes to the lack of systemic support for families living with tongue-tie. Many of the participants believed that there was a lack of support and professional knowledge available, and in turn caused them to question and distrust healthcare professionals' knowledge.

The lack of healthcare support in relation to feeding a child with tongue-tie had a significant effect on the emotional well-being of the participants. Participants told similar stories of going from one healthcare provider to another to try and get answers about their child and the issues they were having with feeding. Many participants discussed how they felt confused and dismissed by the healthcare system, and that they were not being listened to, which was also demonstrated in the study by Edmunds et al.<sup>17</sup>

This is not just the case for breastfeeding mothers of a child with tongue-tie, as “the culture of the healthcare system is widely described as a barrier to breastfeeding across much of the literature reviewed”.<sup>2</sup> Women describe an overall lack of individualized or personalized care, and hospital organizational factors are described as being not helpful, such as: rules that prevent the partner from staying with the new mom and baby; staff shortages; conflicting advice and information; the judgmental attitudes of some health professionals; and even rude, impatient or unprofessional behavior exhibited by health professionals.<sup>2</sup> Poor support from healthcare professionals can decrease a woman's confidence in breastfeeding and therefore result in the early cessation of breastfeeding.<sup>2,82,83</sup> The participants in this current study were possibly having even more

issues than a normal “new” mother, making lack of support a critical hit to their healthcare experience.

In terms of the healthcare received, another issue was the necessity of multiple procedures to get their child’s tongue-tie released. Many of the participants were clearly frustrated that this had been their experience, however this is not unheard of for tongue-tie releases. In the CADTH report,<sup>46</sup> the authors state that there were cases of re-operation in two of the studies reviewed, one reporting at least five cases of re-operation. The CPS position statement<sup>12</sup> states: “there is a risk that postoperative scarring may limit tongue movement even further, necessitating reoperation”. However, many of the participants in this current study believed it was due to a lack of knowledge and education on behalf of their healthcare provider that this was happening.

The participants’ experience of having a child with tongue-tie began to change their perception of the healthcare system. Many of the participants communicated that although they were very close to their family doctors, they felt that they knew more about their issues and began to question their doctor’s knowledge and ability. This questioning of ability was not just limited to family doctors, but to many of the different healthcare professionals they encountered when trying to get help for their child with tongue-tie.

The majority of the participants felt their healthcare providers did not listen to them and their symptoms, and that their issues had been dismissed. Many of the participants felt powerless over their situation. The relationship the participants had been seeking with

their healthcare providers could be described as “shared decision making”, as to give the participants a sense of control over their own situation. However, shared decision making requires attitudes and skills that many physicians may not possess or be familiar with.<sup>84</sup> Partnering with a patient may require physicians to counsel patients about lifestyle issues or attend to patients’ emotional distress.<sup>85</sup> Physicians may also need to negotiate their own professional biases and emotions.<sup>86</sup> Furthermore, studies have shown that when faced with a patient they view as difficult, physicians respond in problematic ways, ranging from avoidance to anger, and they use stereotypes as a form of distancing.<sup>85</sup>

Analyzing the relationship between the participants and their healthcare providers, especially their family doctors, may also be illustrating the changing relationship and healthcare authority of physicians within NL. From a historical basis, physicians within NL had maintained a “God-like”<sup>87</sup> status within society, as they were usually the most educated and “well-off” members of the community.<sup>87</sup> Because of this, many people would not think of questioning their doctor’s opinions or treatments. Andersen et al<sup>87</sup> explored the changing of health care beliefs and practice in NL during the first half of the twentieth century through the recollections of elders from NL. One participant in their research study described how access to the healthcare system had changed, noting that NL is a “different world altogether now” as there is greater access to healthcare providers today. In earlier times, you had to have “faith in your doctor”,<sup>87</sup> implying that there was no one else to help you at that time, you didn’t have any other options besides for the doctor in your community.<sup>87</sup> Another participant in their study added that “the doctor was next door to God”,<sup>87</sup> and that you would never have questioned their authority.

For people who have grown up in NL, these values have been passed on through the generations. The province was used to relying on the word of the doctor, and it was the norm for generations of a family to pass through under the same working physician. For many of the participants in the current study, their experience with their family doctor had now become strained, as they realized that they no longer accepted everything they were told, and began to question their doctor's ability, and sometimes to resent him or her. Changing of healthcare authority is not limited to NL, and has become a common phenomenon in western society.<sup>88</sup> Frosch et al<sup>88</sup> looked at why some patients are reluctant to engage in a collaborative discussion with physicians about their choices in health care. To explore this issue the researchers conducted six focus-group sessions with forty-eight people in the San Francisco Bay Area. One of the women in the focus group reconciles the assumed elevated status of physicians with her-own view of reality:

You have to realize that doctors are just people...and there's a lot they don't know. And... I think you have to always have this...feeling of maybe they're not right. I was brought up in the generation which...elevated doctors to a, a high throne in heaven someplace, and that's just not true. I mean...they know what they know and...there's a lot they just don't know. ...I feel very skeptical sometimes...about what the doctor said. And that's very frightening to me.

Some of the participants in this current study had begun private treatment of cranial sacral therapy to try and alleviate their child's issues post-release. Chiropractic treatment is said to correct restrictions of motion in joints and stimulate optimal function of the nervous system, thereby influencing physiological processes.<sup>89</sup> The treatment consists of

myofascial release of associated soft tissue structures (cranial and submandibular, cervical and tongue muscles), adjustments to the individual cranial bones and spinal vertebrae, lymphatic drainage and light massage techniques and specific stretches or range of motion exercises as indicated.<sup>90</sup> There is no published literature that connects the benefits of cranial sacral therapy to tongue-tie, but the participants in the focus group who had the therapy, believed that it had helped.

It should be noted that not all of the participants had negative experiences with the healthcare system. Many of the participants were quick to point out that some interactions with healthcare providers were positive, but there was no consensus on a specific specialty or type of healthcare professional, rather it was an individual interaction, which was reported as positive. Almost every participant discussed having received care from a different healthcare professional. For example participants may have seen a lactation consultant, a public health nurse, a dentist, or a physician or a combination of the above.

In terms of the participants' experience with release treatments, many of their stories varied. Some participants recounted their experience as fairly positive. These participants were usually able to get a diagnosis relatively quickly, had the release and then were able to see an improvement in their child. These participants also usually referred to the release as something that was quick and simple, and did not consider the release to be a "bad" thing. Other participants had quite a different experience. Some of the participants recalled how it took months to even get a diagnosis of tongue-tie, and even then actually getting the release took a very long time. Some participants stated they had to get

multiple procedures completed prior to seeing improvement, having to fight for the healthcare provider to go back and see if the tongue-tie was indeed removed. Also, some of these participants were unable to get a release completed here in NL that eliminated their issues, and some of them had to fly out of province, and some even country, to get their releases completed. Other negative experiences in terms of the release were how it was completed. Some participants recalled the experience of watching their child getting released as “traumatic”. Within the available literature, there is nothing that accounts for the mother’s perception and experience of the release, however the CADAT review<sup>46</sup> concluded that “overall there is evidence that frenectomy is a safe procedure with demonstration of benefit for short-term breastfeeding effectiveness as perceived by the mother”.

Overall, the participants’ stories about the healthcare they received illustrated a lack of systemic support for tongue-tie. One of the biggest issues was the lack of release care: pre, post and during frenotomy. Many participants reported feeling underprepared to have a release completed, and were even less prepared to deal with the after-care, such as stretches. The participants also discussed the general lack of knowledge surrounding tongue-tie by healthcare providers, even the ones providing support. This caused many of the participants to move from one healthcare provider to the next. The fact that participants were having to go back for multiple procedures because the healthcare provider was not prepared to deal with the child’s tongue-tie, especially if it was a posterior tongue-tie, was quite unsettling. Manipon<sup>18</sup> shares that the child with a posterior tongue-tie is more difficult to assess and is usually identified on manual inspection of the

oral cavity. This form of tongue-tie occurs when the lingual frenulum is thickened and more fibrous, which anchors the tongue to the floor of the mouth without the involvement of the tip of the tongue, impeding mobility.

All of the participants could illustrate how they would have liked their experience to have been different. Some of the participants described elaborate healthcare systems to support a mother of a child with tongue-tie; others added that simply being listened to would have been an improvement. The consensus on an ideal system was one that would support mothers, listen to- and be there for them, if they needed it.

### **5.3 What are mothers' perceptions of their child's ability to feed pre and post tongue-tie release?**

The participants' perceptions of how the tongue-tie release affected feeding practices were fairly consistent: it improved them. Many spoke of the numerous issues their child had before the tongue-tie release, such as awful reflux, lack of weight gain, inability to latch properly, or sometimes just excruciating pain while breastfeeding. Once their child had been released, or revised "properly" to remove the complete tongue-tie, the participants spoke of the relief that they experienced. Their triumphs varied, some were able to breastfeed, some children finally slept through the night, others could finally have relief from their reflux, and some could finally use a sippy cup. No matter the success, all of the participants saw the release as finally helping them. These sentiments were seen within the study performed by Edmunds et al,<sup>17</sup> which spoke of the relief the participants felt once they had their child's tongue-tie diagnosed and treated. The mothers' perceived

freedom from pain following the tongue-tie was echoed in the current study. In addition, in the study by Geddes et al,<sup>31</sup> the mothers reported a significant increase in milk transfer and 24 hour milk production after frenotomy. Within the focus groups some of the participants discussed achievements outside of breastfeeding after frenotomy, such as improved feeding, weight gain, less fussiness, better eating ability and improved articulation. It was reported that in a group of children with a large proportion of major problems with dribbling and excess gas, mother's reported improved feeding (breastfeeding and bottle) in patients who received frenotomy.<sup>91</sup> Studies have also reported neonates gaining significant weight by 15 centiles, two weeks post-frenotomy compared to pre-surgery weight,<sup>15</sup> and a significant reduction in rate of women reporting fussiness of child at the breast after frenotomy.<sup>92</sup>

These individual studies are supported by the CADTH review,<sup>46</sup> which concludes that “overall there is evidence that frenectomy is a safe procedure with demonstration of benefit for short-term breastfeeding effectiveness as perceived by the mother”, which takes into account maternally reported improvement in breastfeeding, latch scores, pain scores, breastfeeding self-efficacy and long term feeding follow-up.

It should be noted that not all participants received the relief they anticipated from the frenotomy. One participant who had multiple releases completed was unable to enjoy her breastfeeding experience. Even though she did feel “an improvement” after the second release, her milk supply was never able to fully come in and is still on numerous medications, and using a supplementary nursing system to feed her child. Also, many of



the participants within the group who had young children released, and saw improvements for their breastfeeding experience, worried if there may still be effects of the tongue-tie later in development, such as eating whole foods, and speech articulation. Overall, the participants within the focus group perceived their ability to feed their child as improved after the releases, and would also be very proactive in ensuring they receive the proper supports and treatments for any future children with tongue-tie they may have as to protect their feeding ability.

## **Chapter 6.0 Strengths, Limitations and Future Research Recommendations**

This chapter will present the strengths, limitations of the present study in terms of the sample population, credibility, and assumptions of the study and will provide areas for the future research.

### **6.1 Strengths**

This study attempted to add to the literature by researching the experiences of mothers who breastfed or attempted to breastfeed their child with tongue-tie. Currently, there is only one other published study that looks at the experiences of mothers with children with tongue-tie. The rest of the published literature focuses on the effectiveness of frenotomy with regards to breastfeeding and child feeding, and does not explore the experiences of the mothers- besides for using nipple pain scores and self-efficacy improvement scales. This study is significant, as within the Western World tongue-tie has become a “hot topic”, in the healthcare system, and mother/breastfeeding support groups. Tongue-tie frenotomys are in high demand, and women are frustrated with the lack of support and inconsistent answers they are receiving. This study contributes documented findings of the experiences mothers are having with regards to their access to support, and the taxing emotional journey of breastfeeding a child with tongue-tie. This research is significant because one can argue that a tongue-tie was not present, or that a frenotomy was not necessary, or even that a tongue-tie is not real, but this is not the point: this research speaks to the fact that mothers within our province are very dissatisfied and upset about their post-natal experiences, to the point of severe emotional distress. This

research is not meant to promote that a frenotomy is for every child with tongue-tie, or that every mother with a child with tongue-tie will have similar experiences, but to address and educate the public and healthcare system of the experiences that some mothers have been undergoing and to hopefully improve the system and support that mothers have access to.

Furthermore, this study gained a large amount of attention from mothers across NL and into the Maritime Provinces as I was contacted by a number of individuals who were interested in participating but were unable due to their location. However, because this research was only for a master's thesis, and the focus groups were only to be conducted in St. John's we were unable to include all the interested mothers. Therefore, this project may act as a pilot project to subsequent research questions that have developed from the findings of this research, as to gain a greater picture of the experiences of mothers of children with tongue-tie within the province of NL.

## **6.2 Limitations**

**6.2.1 Sample Population** The study findings are based on a sample from one location across the province of NL, comprised of participants who were all partnered, educated and relatively well off. The results are therefore limited in transferability to those who volunteered to participate and may not be fully representative of the larger population of mothers who had experience with feeding a child with tongue-tie. However, the results of our study show that mothers who would be considered privileged still suffered greatly

due to their child's tongue-tie and the system in place to support them- indicating the obvious flaws in our healthcare system.

**6.2.2 Credibility** The analysis of data using a qualitative description approach entails that no theoretical strings are attached. This is positive in that the analysis stays close to the data and the informants' points of view.<sup>52</sup> However, this may make the analytical process somewhat subjective, as descriptions will always depend on the researcher's perceptions, inclinations, sensitivities, and sensibilities.<sup>53</sup> However, it is possible to establish both credibility (and rigor) in qualitative description, through ensuring *authenticity*, *criticality* and *integrity*,<sup>60</sup> along with *objectivity*, *transferability*, and *application*<sup>61,62</sup> of the study- as discussed within the methodology chapter. Moreover, the overall credibility of a qualitative description study depends on the researcher's ability to capture an insider perspective and to represent that perspective accurately,<sup>55</sup> which was what I aimed to deliver. However, it should be noted that respondent validation, or member checking, which involves going back to participants to review the findings, generally when data collection and analysis have been completed,<sup>93</sup> was not conducted. However, I did try to clarify what the participants meant by what they said during the focus groups to ensure I was accurately recording their experiences.

**6.2.3 Assumptions** During the data collection phase and the data analysis phase of this study, it was assumed that each participant had offered honest interpretations and perspectives of their experiences. I also assumed that the data collected from the two

focus groups would be sufficient to answer the study's research questions as data saturation (i.e., no new data emerging) had been reached after the second focus group.

### **6.3 Future Research**

Based on the results of this study and the analysis of previous literature, our research group has developed a number of recommendations for future research. One such recommendation is that future research needs to be conducted on the experiences of mothers living in NL outside of St. John's to capture the rural experience of having a child with tongue-tie. St. John's, as the capital city provides greater access to healthcare services, lactation consultants, breastfeeding support groups and frenotomy releases compared to the less populated areas of the province. The experiences of mothers outside this area may be different. Furthermore, as our sample demographic was that of mothers with high levels of education and income, our research findings are limited to this group.

A major point discussed by the participants was the lack of consistency on the diagnosis, assessment and management of tongue-tie by health care providers. Therefore, a research project on healthcare providers' perceptions of tongue-tie could be useful. Furthermore, research is needed to develop a tool to assess and diagnose tongue-tie in a valid and reliable way. Another potential outcome is the development of educational materials and resources for mothers and healthcare providers surrounding tongue-tie assessment, diagnosis and management. Additionally, the impact of these educational interventions could also be studied.

Finally, further long-term research is needed to follow children with tongue-tie who have had releases and those who have not to examine longer-term outcomes such as speech, and other health issues. Also, the possibility of a genetic link for tongue-tie could also be studied. There appears to be an increasing prevalence of tongue-tie-in some cases this can be explained by an autosomal dominant pattern of inheritance,<sup>94,95</sup> which means that prevalence can increase with each new generation and increasing population size.

This research had no underlying theory guiding its design, however, after careful consideration of our results, we realize that the factors/themes that developed from this research may fit well with the Social Ecological model (SEM).<sup>96</sup> The SEM guides health promotion interventions through a theoretical understanding of the relationship of multiple factors at the intrapersonal, interpersonal, organizational, and policy levels and their influence on health and health behavior.<sup>96,97</sup> Application of the SEM could allow for stratification of our data into outcomes and factors at the maternal/infant dyad level, the provider level, the hospital/organizational level, and the systems level. From a future research perspective, it is our belief that our findings could be utilized within the SEM to help increase awareness and understanding of the factors that affect the breastfeeding relationship, especially for a mother of a child with tongue-tie. Furthermore, this model could be employed for specific targeted interventions to improve initiation and duration of breastfeeding.

#### **6.4 Conclusion**

The purpose of this research was to explore the experiences of mothers who have breastfed or attempted to breastfeed a child with tongue-tie. Experiences of feeding a child with tongue-tie varied. Mothers established it had a significant impact on their emotional well-being, negatively affecting both physical and emotional health. Mothers experienced excruciating pain and discomfort while attempting to breastfeed. Feelings of guilt, obsession and being dismissed by society were experienced. Yet, there was evidence of resiliency and self-advocacy, which empowered the mothers. The experience also had a varied impact on relationships, including those with the spouse, other children, friends and family, and healthcare providers. Expectations of breastfeeding were challenged, and made the mothers question current and future feeding decisions. There was a lack of systemic support for families affected by tongue-tie, which in turn caused mothers to question and distrust healthcare professionals' knowledge. Finally, the mothers' perceived the tongue-tie release to be of significant benefit to the overall feeding ability and health of their child.

The study findings are based on a sample from one location across the province of NL, comprised of participants who were all partnered, educated and relatively well off. This research will help inform the larger healthcare community about the experiences of mothers who have breastfed or attempted to breastfeed a child with tongue-tie. It will also aid in the identification of appropriate supports for mothers of children with tongue-tie, and help to inform the development of clinical practice guidelines and regional policies for healthcare professionals.

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**Appendix A: Inclusion Criteria Questionnaire****Inclusion/Exclusion Criteria Questionnaire**

*This questionnaire will be used to collect details about potential participants who have contacted the Principal Investigator to take part in the study. We will use these details to conduct purposive sampling for our focus groups. We are looking to include mothers/birthing parents of a variety of ages and socioeconomic backgrounds. They must also meet the criteria of being over 19 years of age and having breastfed or attempted to breastfeed their tongue-tied infant for any period of time. No identifying details will be attached to the transcript.*

**1. What is your age?**

- ☐ **24 or under**
- ☐ **25-34**
- ☐ **Over 35**

**2. What is the highest level of education you have completed?**

- ☐ **High school or equivalent**
- ☐ **Some college/ university**
- ☐ **College diploma**
- ☐ **Bachelor's degree**
- ☐ **Graduate Degree (e.g. MA, PhD)**
- ☐ **Professional degree (MD, JD, etc.)**
- ☐ **Other**

**3. Age of infant who is tongue-tied? \_\_\_\_\_****4. When did you breastfeed or intend to breastfeed your tongue-tied infant?**

- ☐ **Currently breastfeeding**
- ☐ **Less than 1 month ago**
- ☐ **Less than 6 months ago**
- ☐ **6 months or more ago**
- ☐ **1 year ago**
- ☐ **2 years ago**
- ☐ **3 years ago**
- ☐ **More than 3 years ago**

**5. How long did you breastfeed your tongue-tied infant?**

- ☐ **Less than 1 week**
- ☐ **Less than 1 month**
- ☐ **Less than 6 months**
- ☐ **6 months or more**

- ☐ **Still breastfeeding**
- 6. Are you interesting in attending one focus group, of 1-2 hour length?**
- ☐ **Yes**
  - ☐ **No**
- 7. If yes, please give at least one method to contact you**
- Email:** \_\_\_\_\_
- Phone:** \_\_\_\_\_

**Please note any further questions you have regarding the study can be directed to the principal investigator, Jillian Waterman at jaw130@mun.ca. If you are accepted as a participant for the study, we will contact you to give you further details regarding the study. Thank-you for your time.**

**Appendix B: Recruitment Advertisement**

## **Breastfeeding and Tongue-Tie Focus Group**



**Are you a mother/birthing parent who had breastfed or attempted to breastfeed an infant with tongue-tie?**

**Would you like to take part in a research study?**

*The main purpose of this research is to explore the experiences of mothers and birthing parents who have breastfed or attempted to breastfeed an infant with tongue-tie.*

**We are looking for mothers/birthing parents who...**

- Age 19 and over
- Has breastfed or attempted to breastfeed a tongue-tied infant for any period of time (within the last three years)

**Your involvement will include...**

- One group interview. Each interview will last 1-2 hours.
- Before the group interview begins you will be invited to complete one survey

**For more information about the study, or to ask if you can take part, please contact: Jillian Waterman, at [jaw130@mun.ca](mailto:jaw130@mun.ca)**

**Appendix C: Focus Group Demographic Survey****Focus Group Demographic Questionnaire**

*The purpose of this questionnaire is to collect details about the participants in the study that may not be covered within the focus group session. The information gathered will help the researchers from Memorial University describe the participants interviewed. No identifying details will be attached to the transcript. Please check only one box for each question. Once you have completed the questionnaire please give it to the principal investigator, Jillian Waterman.*

**8. What is your age?**

- ☐ **24 or under**
- ☐ **25-34**
- ☐ **Over 35**

**9. What is the highest level of education you have completed?**

- ☐ **High school or equivalent**
- ☐ **Some college/ university**
- ☐ **College diploma**
- ☐ **Bachelor's degree**
- ☐ **Graduate Degree (e.g. MA, PhD)**
- ☐ **Professional degree (MD, JD, etc.)**
- ☐ **Other**

**10. What is your current marital status?**

- ☐ **Married/ Common-law**
- ☐ **In a relationship but not living together**
- ☐ **Divorced**
- ☐ **Separated**
- ☐ **Single**
- ☐ **Widowed**
- ☐ **Prefer to not answer**

**11. What city or town do you live in? \_\_\_\_\_****12. What is your annual household income?**

- ☐ **Less than \$30,000 per year**
- ☐ **\$30,000-\$60,000 per year**
- ☐ **\$60,000-\$100,000 per year**
- ☐ **Over \$100,000 per year**
- ☐ **Prefer not to say**



**13. Which of the following best describes your current employment?**

- ☐ Homemaker
- ☐ On maternity/parental leave
- ☐ On other leave
- ☐ Student
- ☐ Unemployed
- ☐ Employed full-time
- ☐ Employed part-time
- ☐ Other, please specify \_\_\_\_\_

**14. How many children do you have? \_\_\_\_\_**

**15. If you have children, how many have you breastfeed? \_\_\_\_\_**

**16. How many of your children have been diagnosed with tongue-tie?**  
\_\_\_\_\_

**17. Approximately how old was your infant when the diagnosis of tongue-tie was made? \_\_\_\_\_**

**18. Who diagnosed your child's tongue-tie (i.e. which health professional)?**

- ☐ Pediatrician (in hospital)
- ☐ Family physician
- ☐ Lactation consultant
- ☐ Public Health Nurse
- ☐ Dentist
- ☐ Other: \_\_\_\_\_

**19. Has your child received out-of-province treatment for their tongue-tie?**

- ☐ Yes
- ☐ No

**20. Have you been diagnosed with tongue-tie?**

- ☐ Yes
- ☐ No
- ☐ Not sure

**21. Has the other biological parent been diagnosed with tongue-tie?**

- ☐ Yes
- ☐ No

- **Unsure**

**22. Do you have a parent or sibling who has been diagnosed with tongue-tie?**

- **Yes**
- **No**
- **Not sure**

**23. Has your tongue-tied child received a revision?**

- **Yes**
- **No**

**24. When you were pregnant did you intend to breastfeed?**

- **Yes**
- **No**

**25. Is there anything else you think we should know about your experience of feeding an infant with tongue-tie?**

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*Your answers are very important to this study, and we thank-you for your involvement.*

### **Appendix D: Focus Group Script/Prompts**

#### **Focus Group Prompts**

*The focus group will begin with a greeting and the participants will be given a demographic questionnaire to fill out. Once the questionnaires are collected, there will be a short icebreaker to begin the discussion. The participants will then be informed of the study purposes. The researchers will also review consent issues, such as confidentiality, not having to answer any question they do not want to and the ability to leave the focus group at any point. The researchers will then discuss the procedures, such as how the focus group will be led and conducted, how it is being recorded and that there are no correct answers.*

The initial prompt will be open-ended, giving participants the opportunity to discuss any aspect of their experiences and to focus on the topics they deem most important.

Open-ended prompt: What was your experience of having an infant with tongue-tie?

Depending upon how individual participants respond, the following prompts will be used. All of the ideas listed will be discussed in the focus groups, but not necessarily in the order listed. Qualitative semi-structured interviewing is a collaborative experience, with the researcher and participants actively involved in directing the discussion.

#### *IMPACTS*

1. Do you think your infant's tongue-tie affected your ability to breastfeed? If so, how?
2. How do you think dealing with your infant's tongue-tie affected you personally? (Prompts for physical health, emotional health, relationships, future feeding practices)

#### *TONGUE TIE REVISION*

3. Did your infant receive a revision of their tongue-tie?
4. Do you think this revision affected your infants feeding? If so, how?
5. Would you suggest a tongue-tie revision to another parent?

#### *SUPPORTS*

6. Did you feel you had support through the health care system?

7. Do you feel like you got the supports you needed?
8. As a parent dealing with a tongue-tied infant, where did you feel you received the most positive support?
9. Are there any changes you would like to see in supports for parents of infants with tongue-tie?

Other

10. Is there anything else you would like to tell us about your experience or any further comments?

### Appendix E: Ethics Approval



Ethics Office  
Suite 200, Eastern Trust Building  
95 Bonaventure Avenue  
St. John's, NL  
A1B 2X5

January 12, 2016

Ms Jill Waterman  
3a Alice Drive  
St. John's, NL A1B 4P1

Dear Ms Waterman:

**Reference #15.248**

**RE: Tongue-tie and the Breastfeeding Dyad: Mothers and Birthing Parents' Experiences and Emotional Well-Being**

This will acknowledge receipt of your correspondence.

This correspondence has been reviewed by the Chair under the direction of the Board. **Full board approval** of this research study is granted for one year effective **December 10, 2015**.

**This is your ethics approval only. Organizational approval may also be required.** It is your responsibility to seek the necessary organizational approval from the Regional Health Authority or other organization as appropriate. You can refer to the HREA website for further guidance on organizational approvals.

This is to confirm that the Health Research Ethics Board reviewed and approved or acknowledged the following documents (as indicated):

- Application, approved
- Revised poster, approved
- Revised focus group demographic questionnaire, approved
- Revised consent form, approved

**MARK THE DATE**

**This approval will lapse on December 10, 2016.** It is your responsibility to ensure that the Ethics Renewal form is forwarded to the HREB office prior to the renewal date; you may not receive a reminder. The Ethics Renewal form can be downloaded from the HREB website <http://www.hrea.ca>.

*If you do not return the completed Ethics Renewal form prior to date of renewal:*

email: [info@hrea.ca](mailto:info@hrea.ca)

Phone: 777-6974

FAX: 777-8776

**Appendix F: Consent Form****Consent to Take Part in Research**

**TITLE:** Tongue-tie and the Breastfeeding Dyad: Mothers and Birthing Parents' Experiences and Emotional Well-Being

**INVESTIGATOR(S):**

Jillian Waterman  
Dr. Julia Temple Newhook  
Dr. Tiffany Lee  
Dr. Laurie Twells

You have been invited to take part in a research study. Taking part in this study is voluntary. It is up to you to decide whether to be in the study or not. You can decide not to take part in the study. If you decide to take part, you are free to leave at any time.

Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

Please read this carefully. Take as much time as you like. If you like, take it home to think about for a while. Mark anything you do not understand, or want explained better. After you have read it, please ask questions about anything that is not clear.

The researchers will:

- discuss the study with you
- answer your questions
- keep confidential any information which could identify you personally
- be available during the study to deal with problems and answer questions

**1. Introduction/Background:**

Tongue-tie is characterized by a tight, short and thick membrane under the tongue. This may result in restricted tongue movement. We are looking at how tongue-tie may affect an infant's ability to breastfeed. We are also looking at how this may affect a mother or birthing parents' emotional well being. By conducting this study we hope to hear what mothers and birthing parents' experiences have been with

feeding a tongue-tied infant and their experiences with the healthcare system with regards to having a tongue-tied infant.

**2. Purpose of study:**

The main purpose of this research is to explore the experiences of mothers and birthing parents who have breastfed or attempted to breastfeed an infant with tongue-tie. We also hope to learn about the mothers or birthing parents' experiences with the healthcare system with regards to having a tongue-tied infant, such as any revision treatments received and their feelings about the access to care and available supports from the healthcare system.

**3. Description of the study procedures:**

You will be expected to participate in one group interview. You will either be apart of the group interview in:

- Memorial University's School of Pharmacy, St. John's
- Community Health Office, Eastern Health in Harbour Grace.

Each interview will last 1-2 hours. Before the group interview begins you will complete one demographic survey.

**4. Length of time:**

The interview will last 1-2 hours.

**5. Possible risks and discomforts:**

Risks are minimal.

- Emotional: Speaking about your experience associated with breastfeeding your tongue-tied infant may bring up topics that could be distressing for you. A list of counselling services/resources will be provided.
- Economic/Social: Having to drive to the focus group.
- Social: Taking time out of your day to participate in the focus group.

**6. Benefits:**

It is not known whether this study will benefit you.

**7. Liability statement:**

Signing this form gives us your consent to be in this study. It tells us that you understand the information about the research project. When you sign this form, you do not give up your legal rights. Researchers or agencies involved in this research study still have their legal and professional responsibilities.

## **8. What about my privacy and confidentiality?**

Protecting your privacy is an important part of this study. Every effort to protect your privacy will be made. However it cannot be guaranteed. Other people taking part in this focus group may know your name and hear your comments. All members of the focus group will be reminded to:

- respect the privacy of each member of the group.
- treat all information shared with the group as confidential.

### **When you sign this consent form you give us permission to**

- Collect information from you
- Share information with the people conducting the study
- Share information with the people responsible for protecting your safety

### **Access to records**

The members of the research team will see study records that identify you by name. Other people may need to look at the study records that identify you by name. This might include the research ethics board. You may ask to see the list of these people. They can look at your records only when supervised by a member of the research team.

### **Use of your study information**

The research team will collect and use only the information they need for this research study. This information will include your:

- age
- information from study interview and questionnaire

Your name and contact information will be kept secure by the research team in Newfoundland and Labrador. It will not be shared with others without your permission. Your name will not appear in any report or article published as a result of this study.

Information collected for this study will be kept for five years.

If you decide to withdraw from the study, the information collected up to that time will continue to be used by the research team. It may not be removed. This information will only be used for the purposes of this study.



Information collected and used by the research team will be stored in a locked cabinet in room H3417 at the School of Pharmacy, Health Sciences Centre. Dr. Tiffany Lee is the person responsible for keeping it secure.

**Your access to records**

You may ask the study researcher (Jillian Waterman) to see the information that has been collected about you.

**9. Questions or problems:**

If you have any questions about taking part in this study, you can meet with the investigator who is in charge of the study at this institution. That person is: Jillian Waterman

*Principal Investigator's Name and Phone Number*

Jillian Waterman (709-725-6264)

Or you can talk to someone who is not involved with the study at all, but can advise you on your rights as a participant in a research study. This person can be reached through:

Ethics Office

Health Research Ethics Authority

709-777-6974 or by email at [info@hrea.ca](mailto:info@hrea.ca)

**After signing this consent you will be given a copy.**

HREB Version: June 2014

**Signature Page**

**Study title:** Tongue-tie and the Breastfeeding Dyad: Mothers and Birthing Parents' Experiences and Emotional Well-Being

**Name of Principal Investigator:** Jillian Waterman

**To be filled out and signed by the participant:**

Please check as appropriate:

I have read the consent form.	Yes { }	No { }
I have had the opportunity to ask questions/to discuss this study.	Yes { }	No { }
I have received satisfactory answers to all of my questions.	Yes { }	No { }
I have received enough information about the study.	Yes { }	No { }
I have spoken to <b>Ms. Jillian Waterman</b> and he/she has answered my questions	Yes { }	No { }
I understand that I am free to withdraw from the study	Yes { }	No { }
• at any time		
• without having to give a reason		
I understand that it is my choice to be in the study and that I may not benefit.	Yes { }	No { }
I understand how my privacy is protected and my records kept confidential	Yes { }	No { }
I agree to be audio taped	Yes { }	No { }
 I agree to take part in this study.	 Yes { }	 No { }

\_\_\_\_\_  
Signature of participant\_\_\_\_\_  
Name printed\_\_\_\_\_  
Year Month Day\_\_\_\_\_  
*Signature of witness (if applicable)*\_\_\_\_\_  
*Name printed*\_\_\_\_\_  
*Year Month Day***To be signed by the investigator or person obtaining consent**

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

Jillian Waterman  
Signature of investigator

Jillian Waterman  
Name printed

15/10/27  
Year Month Day

Telephone number: 725-6264

Version date:

-7-

Subject's Initials: \_\_\_\_\_

**Appendix G: List of Counseling Services and Resources****Counseling Services and Resources**

1. The 24-hour Mental Health Crisis line: [1-888-737-4668](tel:1-888-737-4668)
2. The Perinatal Peer to Peer Support group via social media: <https://www.facebook.com/PerinatalPeertoPeerSupportNL/>