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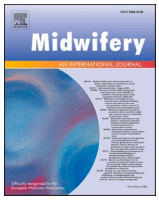

Experiences of tongue tie when breastfeeding twins: A qualitative study

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ABSTRACT

Problem: Tongue tie is an added complication when breastfeeding, but little is known about the role tongue tie might play when breastfeeding twins.

Background: Twins are much less likely to be breastfed than singleton babies due to added complications regarding pregnancy, birth and ongoing care. Tongue tie can cause breastfeeding barriers including poor latch, inefficient milk transfer and nipple pain.

Aim: The aim of this study was to conduct an in-depth exploration of the experiences of mothers who have breastfeed twins with suspected or diagnosed tongue tie.

Methods: Interview and qualitative survey data exploring the experience of breastfeeding twins and multiples were analysed with a focus on the experiences of participants reporting on suspected or diagnosed tongue tie. Data were analysed using reflexive thematic analysis.

Findings: Three themes were developed. These were: 1) feeling disempowered by tongue tie denial; which illustrated the experience of dismissal by healthcare professionals, 2) the avoidable impact of diagnostic delay; highlighting the practical, physical and psychological impact of tongue tie, and 3) improvements following intervention; illustrating the immediate improvements experienced following frenotomy.

Discussion: Mothers who suspect tongue tie find themselves disempowered by denial of their experiences and needing to fight for intervention. Long delays lead to distress for both mother and child while intervention often leads to instant improvement.

Conclusion: Improved healthcare professional training and healthcare policy changes are needed to improve tongue tie support and intervention for parents of twins and reduce the threat to mother and child health and wellbeing.

Statement of Significance: **Problem or Issue:** Breastfeeding rates for twins are much lower than for singleton babies. For some infants tongue tie may be an additional barrier to breastfeeding success.

What is Already Known: Research with parents of singleton babies has shown that tongue tie can cause distress, frustration and physical pain for mothers who report dismissal by healthcare professionals and a need to fight for support.

What this Paper Adds: The voices of parents of infants with tongue tie who have successfully breastfed twins are presented. Like parents of singleton infants, they experienced diagnostic delays and psychological and physical impacts of tongue tie. Intervention was often sought privately when NHS support was lacking. Regardless of source, tongue tie intervention often led to immediate improvement highlighting how the added stresses and challenges created by tongue tie for twin parents could be prevented with appropriate support and intervention following birth.

Introduction

Twins and multiples are much less likely to be breastfed than singleton babies (Östlund et al., 2010; Whitford et al., 2017). Infant feeding in the United Kingdom (UK) has historically been assessed using the Infant Feeding Survey (IFS) conducted between 1975–2010. A new version of this survey was commissioned in 2023; however, data are not yet available (Office for Health Improvement and Disparities, 2023). The most recent data on breastfeeding twins from the 2010 IFS reported that 68% of mothers stopped breastfeeding their twins or multiples by 4–6 months despite wanting to breastfeed for longer (McAndrew et al., 2012). There are several explanations for this low breastfeeding rate and

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barriers include caesarean birth leading to delay in breastfeeding initiation, reduced skin-to-skin contact and issues with first latch (Bennington, 2011). In addition, pre-term birth increases the risk of complications such as reflux and cardiac and respiratory complications which can present challenges for breastfeeding (Leonard, 2003).

Another potential barrier to breastfeeding is Ankyloglossia, more commonly known as tongue tie. Ankyloglossia is the occurrence of an abnormally short lingual frenulum which can restrict mobility of the tongue and result in breastfeeding difficulties such as problems with latch, nipple pain, and poor infant weight gain (National Institute for Clinical Excellence, 2005). The overall prevalence of tongue tie in children under 1 year of age is reported to be 8% (Hill et al., 2021). Frenotomy is the recommended treatment and is a relatively low risk and well tolerated procedure during which sharp, blunt-ended scissors are used to divide the lingual frenulum (National Institute for Clinical Excellence, 2005). While the value of frenotomy is debated, a recent meta-analysis has reported that infant frenotomy reduces breastfeeding difficulty and maternal pain with the potential to increase breastfeeding duration and exclusivity (Bruney et al., 2022). Similarly, a scoping review has reported that most tongue tie release mechanisms have been found to significantly improve the anatomical limitation of the tongue (Arena et al., 2022).

Some qualitative studies have explored the experience of tongue tie from the mothers' perspective following the birth of singleton babies. A qualitative descriptive content analysis of focus groups with 16 Canadian mothers highlighted experiences of physical pain and desperation but also resilience, the potential for relationship strain with wider family and disagreements about how tongue tie should be dealt with, and feelings of distrust and dismissal by healthcare professionals (Waterman et al., 2021). In Australia, a phenomenological multiple interview study with 10 mothers highlighted how the breastfeeding experience with tongue tie failed to meet mothers' expectations resulting in distress and frustration (Edmunds et al., 2013). Mothers also reported a perceived lack of knowledge by healthcare professionals and that tongue tie was often attributed by staff to 'normal' breastfeeding problems. In this study those who underwent frenotomy reported an immediate sense of relief, reduction in pain and breastfeeding improvement (Edmunds et al., 2013). In the UK a qualitative interview study with general practitioners, midwives, health visitors and mothers explored the facilitators and barriers to tongue tie diagnosis and treatment, reporting that mothers shared stories of fighting for support, diagnostic and treatment delays and ongoing distress as well as a perception of varying professional knowledge about tongue tie (Wakelin et al., 2017).

Much of the research in this area has focused on singleton babies. In a previous report exploring the general experience of breastfeeding twins and multiples it was highlighted that tongue tie can be a concern for this group, particularly regarding weight gain for infants (Cassidy et al., 2024). A full exploration of this phenomena was beyond the scope of the original paper and therefore a detailed account of the experiences of mothers of twins or multiples with tongue tie is needed. Given that breastfeeding rates for twins and multiples are known to be lower than for singleton births, this knowledge will be of value to the future development of healthcare policies and the design of breastfeeding support services to improve breastfeeding rates in twins. This paper reports on analysis of the (Cassidy et al., 2024) data conducting a more in-depth and focussed exploration of the experiences of mothers who have breastfeed twins with suspected or diagnosed tongue tie and addressing the research question "In what ways do mothers perceive the presence of tongue tie to influence their experience of breastfeeding twins?"

Methods

Ethical approval for this research was granted by Univeristy of Staffordshire Health, Education, Policing and Sciences Ethics Committee.

Design

A qualitative design informed by a critical realist ontology and contextualist epistemology was employed. Critical realism acknowledges that reality exists independently of an individuals' ideas about or descriptions of that reality, however that reality is not directly available to researchers. A contextualist ontological position advocates that descriptions of an individual's reality are influenced by language and culture which limit and constrain the world we live within and how we can present that world to others. This stance advocates that there are different and equally valid possible interpretations of participants reality, and that findings and themes presented in research are bound by the contextual lens of the researcher (Braun and Clarke, 2022). To provide context for the reader regarding the lens through which the analysis has been conducted, details about the social worlds of the research team and their relationship to the topic of interest are included within the reflexivity section.

Setting

The research was carried out nationwide in the UK which has one of the lowest breastfeeding rates in Europe (National Services Scotland, 2019; Public Health England, 2021). In the UK breastfeeding support is accessed free of charge through the National Health Service (NHS) and social services in addition to through charity and voluntary sector organisations, however support options are not of consistent quality or availability across the country (Grant et al., 2018). Tongue tie services also vary across the country with differences in relation to the healthcare professional acting as first point of contact, referral criteria, and waiting times for assessment and treatment (Carter et al., 2023)

Sample

Data were collected during a wider study in which mothers with recent experience of breastfeeding twins were recruited. The study used convenience sampling via social media adverts (e.g. Twitter/X and Facebook) and snowball sampling whereby those who saw the advert were asked to share it with their networks. The recruited participants completed an online qualitative survey and/or in-depth interview about their experiences (Cassidy et al., 2024). To take part participants needed to be: 1) over 18 years old, 2) able to converse in English, 3) currently breastfeeding twins or multiples or have experience of breastfeeding twins or multiples in the last two years to aid recall of experience.

For the present study reported cases of diagnosed or suspected tongue tie (n=33, 32% of the original sample) were identified and their data extracted. The original study employed interviews and qualitative surveys; some participants contributed data in both formats. Within the data extracted for the present study 25 participants completed the qualitative survey only, 3 completed both the qualitative survey and interview, and 5 completed the interview only. The sample was necessarily restricted by the size of the original study sample and the number of tongue tie cases within that sample. However, the extracted survey sample size meets the criteria for a small study using participant generated textual material and the adequacy of this sample is bolstered by the addition of in-depth interviews which represent an appropriate sample for a small study using interactive data collection methods (Braun and Clarke, 2013). In the extracted sample ages ranged from 25–46 (mean age 36) and 73% were breastfeeding at least one child at the time of participation (further demographic information can be seen in Table 1).

Data collection

The study was advertised, and data collected in June and July 2022. Interested participants followed a weblink to an information sheet, consent form and online survey about the experience of breastfeeding

Table 1
Participant demographics.

	Count	%
Sample size	33	100
Age		
Max	46	
Min	25	
Mean	36	
Number of children		
Max	5	
Min	2	
Mean	3	
Currently breastfeeding		
Yes	24	73
No	9	27
Relationship status		
Married	24	73
In a relationship	8	24
Single	1	3
Sexual Orientation		
Heterosexual	31	94
Bisexual	1	3
Prefer not to say	1	3
Ethnicity		
White British	28	85
White Irish	1	3
White Other	1	3
British unspecified	3	9
Education		
Further	4	12
Higher	18	55
Postgraduate	10	30
Doctoral	1	3
Employment status		
Employed	17	52
Maternity leave	13	39
Full time parent	2	5
Other	1	3
Location		
England	29	88
Scotland	2	6
UK unspecified	2	6

twins. At the end of the survey a further opportunity to take part in an in-depth interview was offered. Some chose to take part in the interview but did not complete the qualitative survey questions. The online survey and interviews included the same questions (see supplementary material 1). However, during interviews this schedule of questions was used flexibly and prompts and clarifying questions were used when required to elicit more detailed responses from the participant or to explore issues raised in more depth. The in-depth interviews lasted around 1 hour and were completed via Microsoft Teams in English, recorded, and transcribed verbatim. All names and identifying information were removed from the survey responses and during transcription of interview data. All participants were allocated pseudonyms to ensure anonymity. Recordings were stored on the University secure online server and deleted following transcription. Following participation, a debrief sheet with information about sources of support was emailed to all participants.

Data analysis

Extracted data were analysed using Reflexive Thematic Analysis (Braun and Clarke, 2022). All extracts were read by HC and AB to develop familiarity. HC and AB made initial notes on elements of interest in the data then AB created a word document with two columns; data extracts were placed in the first column and the second column was used to make detailed coding notes. All coding notes were then extracted by AB and sorted to create themes. For example, the codes "HCP denial of tongue tie", "feeling unsupported by healthcare professionals" and "frustration at the lack of HCP support/understanding" were part of a group that later formed the theme "feeling disempowered by tongue tie denial". Extracts relating to each code were reviewed by AB and short thematic summaries created. Summaries were used by AB to develop the analysis structure and quotes were selected to illustrate the themes. This framework was used by AB to develop the final thematic narrative which was reviewed by AO and JT.

Reflexivity

Interviews were conducted by HC, a female psychology undergraduate student and mother of a teenage daughter who had been breastfed as an infant. HC transcribed and made notes on the interviews. AB led the analysis and is a mother of two children who were both exclusively breastfed for the first 6 months and then breastfed to beyond 12 months. Her youngest was breastfed following diagnosis and treatment of tongue tie by the National Health Service (NHS). AO contributed to the analysis and is a mother to two young children who were both breastfed beyond 12 months and neither experienced tongue tie. JT contributed to the analysis and was pregnant with her first child at the time of the study. As AB led the analysis, she kept a reflexive journal throughout the process to examine the contributions of her contextual knowledge of the experience to the data analysis process. These observations were discussed and interrogated through regular meetings with AO and JT to ensure the development of themes was grounded in the participant accounts.

Results

Three themes were developed: 1) feeling disempowered by tongue tie denial, 2) the avoidable impact of diagnostic delay and 3) improvements following intervention. All quotes in the following thematic narrative are labelled using pseudonyms. These quotes represent contributions to either survey responses or interview responses provided by mothers with experience of breastfeeding twins. Further example quotes for each theme are available as supplementary material (See supplementary material 2)

Feeling disempowered by tongue tie denial

Participants felt that, despite their experiences and suspicions of tongue tie, their questions about diagnosis and pleas for support were often downplayed, disputed or ignored by the healthcare professionals they encountered. These experiences were disempowering and resulted in mothers questioning their intuition and bodily experiences.

Many described their suspicions of tongue tie being dismissed or denied by NHS employed healthcare professionals:

> *[The healthcare professionals said] "They're premature. They can't latch without nipple shields". But they can't latch because they've got massive tongue ties that you've been denying for two weeks. "Oh no, that* no no *no, no. They look. They can take a bottle." No, they can't, see that milk gushing out the sides of their mouth? That'll be the tongue ties. "Ohh no, they're not tongue tied. They're just little." Right so you're asking me to latch them on to a nipple shield. That's bigger than my nipple. Because that's easier for them. But their mouths are just little, which is why all the milk's tipping out. (Sam, Interview)*

> *Twin 2 had a tongue tie and struggled to breastfeed effectively for months. I had to push to have this diagnosed as the paediatrician was "not concerned". (Emma, Survey)*

These examples illustrate how mothers' bodily experiences and intuition were not prioritised. One participant described how, following a lack of support from NHS staff, they reached out to a private healthcare provider. This again did not resolve the issue, and their observations were dismissed for a second time:

> *I asked the hospital, I said, "are they tongue, is there a tongue tie, do you think?" And the hospital just said "Ohh, that's that we don't check for that. That's nothing to do with us" […] I paid for [an] IBCLC*

(International Board Certified Lactation Consultant) to come out. And she was, I'll be honest, she wasn't really that much use […] she checked the latches. She said she thought it looked fine and she said she didn't think that they had tongue tie. (Anna, Interview)

These experiences left participants feeling unsupported and frustrated. For many, it took additional factors, such as infant weight changes, before support was offered (e.g "*We had tongue tie in both twins, and it was only when weight dropped and my HV really supported us, we got it sorted*" Heather, Survey). For several participants, the constant denial and suggestion that there should be no breastfeeding concerns made them doubt themselves:

The entire time I'd been in hospital, I was told I was imagining their tongue ties. They were just small […] [healthcare professionals had implied] it was my fault because I wouldn't persevere with the [nipple] shield and it was my fault because I was just making problems and it was all my fault. So, I had three weeks of quite hefty gas lighting from the hospital and I came out pretty broken in terms of like, just, I have really strong ideas about what I wanted to do parenting wise and I came out questioning everything! (Sam, Interview)

Sam's ongoing frustration was palpable, not only had the experience resulted in challenges feeding, but the lack of trust of her observations had led her to question everything about her parenting choices. The powerful language of being 'pretty broken' emphasises the physical and psychological impact of the challenges faced discussed further in the next theme.

Several participants acknowledged that they felt the responses from healthcare professionals were grounded in a lack of training and awareness about breastfeeding and breastfeeding support:

There was no one in the hospital who was obviously trained properly for for breastfeeding because every single person said, "oh, they've got a good latch", and the the person who came and did the frenectomy said to us, you can't tell tongue tie by looking because, she's like "it might look like they've got a good latch, but you've got to put your finger and feel for what the tongue's doing", and she's like, because their tongues couldn't do the movement properly they were like clamping with their jaws so it looked like they were kind of tight on the nipple. But actually, they weren't, their tongues weren't doing anything and underneath or to get the milk out properly. So, I guess someone with some sort of actual knowledge in the hospital would have been, would have been good. (Caroline, Interview)

Despite being quickly referred for tongue tie assessment, Laura also discussed the challenges of limited training, describing how she felt the midwife lacked the knowledge and confidence to make the diagnosis:

When they did the check that that first day they said they thought he was tongue tied and he was like it was a really obvious (laugh) tongue tie, but they said that the midwife would have to assess when they came for the home visit. So she did, but she was very new and not very confident, she was like, "yeah, I think so, but I can't like definitely say so". (Laura, Interview)

These examples highlight how interactions with healthcare professionals were disempowering and distressing and could be barriers to quick referral, diagnosis and intervention resulting in avoidable impacts.

The avoidable impact of diagnostic delay

Diagnostic delays had psychological and physical consequences. Psychological impacts typically encountered were self-doubt in addition to anger, frustration and distress, while physical impacts included pain and feeding challenges.

Sam experienced a protracted process for diagnosis and encountered several healthcare professionals who dismissed her concerns. These multiple negative interactions and delays left her feeling angry and critical of the healthcare service:

Now, I am rage-y, I want to make change, but I know that it is a waste of my energy to try and tackle the hospital directly because they will do naff all about it because it's a culture in there to deny tongue tie exists (Sam, Interview)

Similarly, Caroline had raised concerns that *"something wasn't right"* but these had been dismissed by healthcare providers resulting in both Caroline and her baby becoming distressed each time she tried to breastfeed:

She was obviously trying to feed and couldn't do it and was getting more and more upset. […] I tried to cuddle her, she tried to feed and then it would upset her again, so she ended up sitting on my husband, on the sofa. And I was just sat on the floor, crying my eyes out thinking I can't. I've got to give this up I can't do it anymore this is horrible (Caroline, Interview)

For Caroline the constant psychological impacts of struggling to breastfeed and the seeing her infant become distressed were risks for breastfeeding cessation. In addition to avoidable psychological consequences, delays also had physical outcomes such as pain and additional barrier to breastfeeding continuation:

It was a month of, you know, fairly excruciating feeds of really struggling every single time. (Laura, Interview)

I was experiencing a lot of pain with the tongue with their tongue tie. (Charlotte, Interview)

Many felt it was healthcare policy that created delays. For example, several noted an illogical situation whereby if they were offering expressed milk or formula when directly feeding from the breast was not possible then they were not eligible for support:

They told me that as I was bottle feeding them, I didn't qualify for support. I was only bottle feeding because they had tongue tie and couldn't feed properly on the breast. (Caroline, Survey)

It was like very challenging breastfeeding a completely tongue-tied baby, and I honestly think actually, if he hadn't been a twin, we wouldn't have managed. I think because the other twin was latching on really well and stimulating the letdown. Actually, all he had to do there was lie with him with his mouth open and catch it. I think it would have been so much harder if if sort of hadn't had that, bizarrely. So, we then yeah, We went back for the second assessment after Christmas, and they're like, "yeah, yeah, and you can only you can only be referred [for tongue tie] if you're like exclusively breastfeeding." So how people are supposed to get through that? (Laura, Interview)

Caroline was unable to access support as she had bottle fed her infant due to the tongue tie challenges being too great, while Laura had been continuing to directly breastfeed her tongue-tied infant which meant she was eligible for referral. Laura highlighted the struggle of this experience and the unexpected benefit of the second twin feeding well enabling the tongue-tied twin to receive breast milk. The policy put some parents in an impossible position whereby they could never access the support they needed, and Laura felt lucky for receiving the referral.

Participants felt that even healthcare professionals viewed policy barriers to intervention as problematic (*[they said] "yeah, it's just our policy. It's a bit silly, isn't it. We agree with you, but there's nothing we can do.", Caroline, Interview*). Others felt a lack of communication between different healthcare professionals contributed to confusion and delay:

I felt like I was fighting a brick wall for a little bit there, and I'm saying it was the same [area], it's like they don't talk to each other. You know, the hospital was like, "no, we don't recognize [tongue tie]", yet the minute you go home, and you talk to the health visitor, they do recognise it, and it can be divided. And yet it's all the same NHS service. That seemed really silly because you know [my daughter] had tongue tie and she wasn't

gaining weight and couldn't breastfeed, and we were waiting on her to breastfeed to come home (Gabi, Interview)

Gabi's recounted a commonly discussed experience whereby the lack of support to breastfeed had an impact on infant weight and therefore the time spent in hospital before discharge. Gabi's imagery of a 'brick wall' emphasises the disempowering nature of this experience and how she needed to fight for the support needed. Laura also explained the need for improved systems but showed awareness of debates around the appropriateness of tongue tie intervention:

We should have a better system in process, and I know there's a lot of sort of contention around tongue tie and, and what it is and what it means for feeding and whether or not the release is effective. Certainly, in my case it was, and it would have been better if it had been done sooner, and I know I know it's not a fix all for everybody's problems, but in in my case it. It did make a big difference. (Laura, Interview)

This theme has illustrated the psychological and physical impacts of delayed diagnosis and how issues with communication and policies were perceived to contribute to delays.

Improvements following intervention

The journey to tongue tie intervention was often long, slow and with many missed opportunities for support both prior to and following hospital discharge. Despite this, most participants described immediate improvements following tongue tie intervention.

Some participants had not always been aware of their infant having tongue tie. For example, Sophia became aware only after having used formula top-ups before discharge from hospital: "*Twin 2 couldn't latch as well as his brother and needed formula top-ups in hospital only (later found out this was tongue tie) (Sophia, Survey)*". Others who suspected tongue tie experienced constant barriers including cancelled appointments ("*Our tongue-tie appointments were cancelled*", Josie, Survey) and long delays ("*1 tongue tie which due to lockdown wasn't sorted until 5 months old", Gemma, Survey*). Descriptions of missed opportunities to diagnose or offer support for tongue tie were common:

No one checked the twins for tongue tie when we left hospital (it had been noticed in hospital but community [midwives] didn't check) (Lucy, Survey)

My twins had tongue tie and this was repeatedly missed. (Alice, Survey)

Only one participant specifically mentioned quick access to tongue tie intervention ("*Twin 2 also had a tongue tie so I ended up with sore nipples. Luckily this was resolved pretty quickly*", Martha, Survey). However, it is unclear if this was an NHS opportunity, or one sought privately. Seeking private support and intervention was mentioned by many participants as the only way to get support:

Serious tongue tie not picked up and was ignored when I questioned. Had to go private in the end. (Hannah, Survey)

We went to a private breastfeeding consultant and had one of the girls' tongue ties snipped. (Amelia, Interview)

Whether through NHS or private intervention the eventual diagnosis and treatment for tongue tie resulted in, for many, immediate improvements. This included improved latch, comfort and transfer of milk and finally feeling validated. For example, Anna, who felt dismissed by hospital staff and a private professional, experienced the eventual diagnosis as a relief:

I was thinking "oh I feel a bit silly now if I'm wasting their time, so should I cancel that hospital appointment", but I thought "no, I'll go. I'll go to it [tongue tie appointment] anyway". Went to it, it was an NHS hospital […] the woman there said they had a really significant posterior tongue tie, and she said that she couldn't believe that we'd even managed to be breastfeeding. So, it was the frustration of thinking like, I asked on day two or three in the hospital, "did they have a tongue tie?" […] the woman snipped the tongue tie. I think on the the score, whatever the scoring system is, one was a four and the other one was a five, so she said it was really, it was quite bad, so that they were eleven weeks old then when they were snipped and then their weight gain just shot up massively after that. (Anna, Interview)

Anna had been through a complex journey of attempting to breastfeed, topping up with formula, pumping and bottle-feeding expressed breastmilk. It had been stressful and exhausting and resulted in understandable anger and frustration that her initial queries had been ignored. Like Anna, many emphasised the immediate improvements experienced including an ability to continue breastfeeding and relief from pain:

Both needed a cut for tongue tie which made a massive difference (Heather, Survey)

The moment they was cut, because I had one baby's done first just to see how it was, and I instantly could tell that there was a lot less painful. (Charlotte, Interview)

They just weren't feeding effectively and had a very loose latch. I had their tongue tie division and carried on feeding (Darcie, Survey)

For a minority of participants breastfeeding did not improve after tongue tie intervention and further support was required:

Even after treatment he struggled to transfer milk effectively due to a high palate and required on going top ups via supplementary nursing system or bottle for around 8 months. We eventually got to exclusive breast feeding (and solids) and are continuing breastfeeding both to beyond 2 years corrected. (Emma, Survey)

Poor latch due to tongue ties, once these were snipped it didn't get better, I used nipple shields for the first 2 months. […] T2 took a whilst [sic] to develop a deep latch, even after the tongue tie was cut. (Sharon, Survey)

Despite tongue tie not having the immediate improvements hoped for by these participants, it did appear to be the first step and, with perseverance, led to eventual success.

Discussion

This study reports on a focussed analysis of interview and qualitative survey data exploring mothers' experiences of breastfeeding twins. Data from 33 accounts were analysed to understand perceptions of how infant tongue tie may have influenced these experiences. Through analysis three themes were developed: 1) feeling disempowered by tongue tie denial, 2) the avoidable impact of diagnostic delay and 3) improvements following intervention.

Disbelief and dismissal by healthcare providers was challenging and distressing. These experiences led to some mothers doubting their own perceptions of the challenges they were experiencing and left them feeling confused and disempowered. This mirrors findings in Canada where mothers of singleton babies with tongue tie highlighted similar experiences (Waterman et al., 2021). For parents of twins there are added challenges which limit the scope of their decision making regarding their infants, such as pre-term birth, NICU experiences and other health complications (Bennington, 2011; Harvey et al., 2014; Leonard, 2003). The choice to breastfeed is often an important contributor to an individual's motherhood identity (Brown, 2019; Burton et al., 2021) and can be empowering (Drouin, 2013). For mothers of twins, breastfeeding may therefore provide an opportunity for control and choice in an otherwise challenging and disempowering situation (Cassidy et al., 2024). The participants described how tongue tie is experienced as a barrier to breastfeeding and is an added stressor which is amplified by a lack of adequate communication and support from healthcare professionals. Participants felt that this lack of support may result from inadequate training regarding breastfeeding support as has been highlighted in past research (Turville et al., 2022), and reflects the

perceived lack of tongue tie knowledge in healthcare professionals expressed by mothers of singleton babies (Edmunds et al., 2013; Wakelin et al., 2017; Waterman et al., 2021). Participants in the present study also highlighted a seeming consensus by healthcare professionals that breastfeeding twins is too difficult. This healthcare professional stance fails to acknowledge the importance of breastfeeding for some mothers of twins (Cassidy et al., 2024).

These accounts have illustrated how opportunities to listen to mothers, support them and empower them were missed by healthcare providers resulting in anger, frustration and distress and changes in support are needed to prevent similar experiences in the future. Training has been shown to be well received and improve breastfeeding support self-efficacy and practice in healthcare professionals in Sweden (Blixt et al., 2023; Gerhardsson et al., 2023). Such approaches were advocated by participants in this study and show promise. Therefore, the development of new interventions and training programmes regarding breastfeeding support and tongue tie awareness must be prioritised in the UK. This is needed to improve patient interactions with healthcare professionals which can be a major barrier to breastfeeding success and have serious physical and psychological consequences.

Lack of support and diagnostic delay caused a range of avoidable physical and psychological impacts. The accounts depicted the process of obtaining diagnosis and intervention as challenging and drawn-out. While waiting, and fighting for, intervention some mothers experienced pain and psychological distress, factors which have been reported in other tongue tie studies (Edmunds et al., 2013; Wakelin et al., 2017; Waterman et al., 2021) These delays and added stresses put mothers at greater risk of postnatal depression (Brown et al., 2016). Furthermore, breastfeeding protects maternal wellbeing both physically (Kendall-Tackett, 2007) and psychologically (Brown, 2019) and could therefore be particularly beneficial for mothers of twins for whom the added challenges of parenting two infants can increase stress (Kehoe et al., 2016).

The participants described and reflected on perceived policy barriers which prevented support access. For example, several indicated that healthcare professionals were unable to make tongue tie referrals if parents were bottle feeding their infants. Tongue tie referral policies vary across the UK and are impacted by commissioning guidance and investment in tongue tie support (Carter et al., 2023). Many services are unable to accept referral if an infant is receiving formula or is receiving only limited breastmilk (Cambridge University Hospitals, 2024; King's College Hospital NHS Foundation Trust, 2024). This creates an impossible situation for parents of babies with tongue tie who want to continue breastfeeding. If their child is gaining insufficient weight due to poor milk transfer or breastfeeding is causing pain then offering formula becomes their only option, however by offering formula they also lose their eligibility for tongue tie referral therefore removing their choice to be able to breastfeed their child. The participants in the present study highlighted this as a source of distress. As breastfeeding rates for twins are already lower than singleton babies (McAndrew et al., 2012), policies need to be reviewed to ensure that unnecessary barriers to breastfeeding support for twins are not exacerbated by policy referral criteria. These findings illustrate the importance of timely support and tongue tie assessment, and where necessary intervention, for mothers wishing to breastfeed their twins.

Previous research has largely focussed on barriers and deficits linked to tongue tie (Wakelin et al., 2017; Waterman et al., 2021), however the findings of this study also illustrate examples of improvements following intervention. Frenotomy is the recommended medical modality for addressing tongue tie (NICE, 2015) with intervention having potential to improve breastfeeding outcomes (Arena et al., 2022; Bruney et al., 2022). These accounts illustrate how, for many mothers of twins, frenotomy was perceived to result in instant improvements including reduced distress and pain and increased weight gain for their infant, mirroring the improvements following intervention reported by Australian mothers of singleton babies (Edmunds et al., 2013). A minority of mothers reported frenotomy did not cause immediate improvement. However, for these individuals the tongue tie intervention meant they had been listened to and their concerns had been validated, it also appeared to be a first step and resulted in continued breastfeeding rather than cessation. These improvements are important for twin parents and targeted identification and intervention for tongue tie could therefore go some way towards addressing the reduced rates of breastfeeding reported for twin births.

For many, the quickest way to receive support and to ensure they could continue to breastfeed was to seek out private healthcare. This is not representative of most of the UK population for whom private healthcare is beyond their financial means. This is symptomatic of a healthcare system with systemic inequalities in maternity care access, experiences and outcomes (MacLellan et al., 2022; Rayment-Jones et al., 2019) and highlights a need for targeted improvements to maternity and breastfeeding support for parents of twins to ensure all can achieve their breastfeeding goals.

Strengths and limitations

Qualitative methods are well placed to explore in-depth, contextualised and detailed understandings of psychological and healthcare phenomena (Pope et al., 2002; Willig, 2019) and the present study has been able to present a detailed account of the experience of tongue tie for mothers of twins. However, it is important to acknowledge that tongue tie was not a key focus of the interview schedule or online questionnaire for the original study. Some of the contributions used for this analysis were short and lacked detail, however a large proportion of participants raised the issue of tongue tie without prompting, highlighting that this is an important concern for mothers of twins. It should be noted that other participants in the original study may have experienced tongue tie but chosen not to share these experiences in response to the general questions. In addition, 104 participants contributed to the original research study and of these 33 have been included in this secondary analysis indicating that around 32% of mothers in the twins and multiples sample had suspected or confirmed tongue tie. While it is important to acknowledge that this is a convenience sample and may not be fully representative it is also of interest that the rate of tongue tie reported is substantially higher than the estimated 8% of infants with tongue tie in the general population (Hill et al., 2021). This is suggestive that the prevalence of tongue tie in twins may be a valuable area to explore in future research. In addition, this study was only able to provide insight into the short-term benefits of tongue tie intervention. The use of tongue tie interventions is widely debated, and little is known about the longer-term impacts or value and is therefore an area in need of further research.

This research was conducted within a UK healthcare context in which antenatal support is provided through the free at the point of access NHS. This means transferability of the findings to other healthcare contexts may be limited. However, some of the experiences mirror those reported by parents in Canada (Waterman et al., 2021) and Australia (Edmunds et al., 2013; Waterman et al., 2021) suggesting that challenges with tongue tie recognition and support are evident across several Western countries which have a mix of private insurance based and government funded healthcare systems. In addition, the participant sample were largely white, well-educated and of high socioeconomic status which limits the transferability of these findings beyond this group. The ability of many in the sample to seek private healthcare reflects the high levels of education and socio-economic status of the participants. Many parents in the UK and elsewhere do not have the privilege and resources required to finance private healthcare. These individuals are therefore underrepresented and may experience further distress and disadvantage. Inequality in breastfeeding and tongue tie support should be a priority area for future research.

Finally, data were collected soon after the Covid-19 pandemic. During this time postnatal services in the UK were substantially reduced

(Sanders and Blaylock, 2021) and this may mean that the delays in support reported were more commonly experienced than they would have been at other times. However, research prior to the pandemic has also raised the need to fight for services and the potential for diagnostic and treatment delay (Wakelin et al., 2017) and evidence suggests that tongue tie referral varies substantially across the UK (Carter et al., 2023). Therefore, these accounts may align with current service provision. Further research would be valuable to clarify the current experiences of tongue tie care for twins.

Conclusions

This is the first study to explore the tongue tie experiences of mothers who were breastfeeding twins. Parents of twins are already at higher risk of stress due to increased likelihood of premature birth and birth complications and the added difficulties of raising two children rather than one. Breastfeeding is important to the identity of many mothers, however the preferences of mothers of twins are often dismissed by healthcare professionals when they raise a desire to breastfeed (Cassidy et al., 2024). The findings of the present study have highlighted how challenges are amplified when infants experience tongue tie and has illustrated how interactions with healthcare professionals can serve to undermine and dismiss parental concerns, challenges of diagnostic delay can result in physical and psychological impacts, and the value of prompt support and intervention for continued breastfeeding. These findings advocate for improved healthcare professional training and policy change to enhance tongue tie support and intervention and reduce unnecessary physical and psychological challenges following birth. Furthermore, larger scale studies exploring the prevalence, experience and impact of tongue-tie in twin births are needed to ascertain the scope of these challenges. Changes are needed to reduce the threat that unidentified and untreated tongue tie poses to breastfeeding continuation and wellbeing for twins and their parents, and to empower mothers of twins to make and enact their own choices regarding infant feeding.

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CRediT authorship contribution statement

A.E. Burton: Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization. **H. Cassidy:** Writing – original draft, Project administration, Methodology, Investigation, Conceptualization. **J. Taylor:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization. **A. Owen:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.midw.2025.104282.

Data availability

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions. Participants did not explicitly consent to data being held in a public repository.

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