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Title Page:

Establishing breast feeding in babies with Down's syndrome: the FADES cohort experience

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Abstract:

Objective: To describe breast feeding prevalence, and maternal experience in infants with Trisomy 21.

Design: Longitudinal cohort study

Setting: Participants from UK recruited through websites, social media and local collaborators: neonatologists, community paediatricians and research nurses.

Subjects: Babies under the age of 8 months with Down's syndrome (DS) recruited between the 1st September 2014 to 31st August 2017. Seventy participants: median age 20 weeks (Interquartile range (IQR) 13, 29 weeks) at initial questionnaire.

Main outcome measure: Breastfeeding prevalence at 6 weeks and 6 months amongst babies with DS.

Results: The prevalence of exclusive breastfeeding amongst study participants was similar to the general population (21% vs 23% at 6 weeks, 4% vs 1% at 6 months). However, the prevalence of breastfeeding (exclusive or combination feeding) amongst the study participants was higher than the general population (64% vs 55% at 6 weeks, 54% vs 34% at 6 months).

Conclusion: Although there may be challenges in establishing breastfeeding in babies with DS, our data suggest that exclusive breastfeeding is possible for some, and the prevalence of breastfeeding is comparable to the prevalence in the general population.

Trial Registration: ISRCTN 12415856

Keywords: Down's Syndrome, Trisomy 21, Feeding, Breast-feeding,

Background

Down's syndrome (DS) is caused by trisomy of chromosome 21. DS is usually diagnosed in the first few days of life by recognition of salient features (1). A number of associated conditions including congenital heart disease and gastrointestinal complications can cause additional challenges during the neonatal period. Infants with DS may have oral, anatomical and physiological abnormalities affecting their ability to feed normally: as with other features of DS there is phenotypic variability. To breastfeed effectively, a tight oral/nipple seal needs to be induced with the tongue making a groove and the lips sealing around the nipple. For a baby with DS, the flattened shape of the tongue and low tone in the oral structures means that establishing breastfeeding may be challenging. (2,3). Lewis et al reported that 40% of DS babies had been NG tube fed during the neonatal period illustrating some of the issues with feeding (4). Current World Health Organisation (WHO) recommendations are that babies should be exclusively breastfed until 6 months (5), this is based on the health benefits for mother and baby. Prolonged exclusive breastfeeding is possibly protective against some autoimmune conditions including type 1 diabetes and coeliac disease for which children with DS are at increased risk (6,7,8). Furthermore, there is evidence that breastfeeding exclusively or combined feeding to a lesser but significant extent, enhances immunity and is protective against otitis media and respiratory tract infections (9) both being more prevalent in children with DS (10).

Many countries have registers which provide data on people with DS. These have facilitated retrospective studies providing statistics on for example: birth and death rates and congenital anomalies. However longitudinal birth cohort studies of infants with DS in the UK are rare (11,12,13,14). The FADES (Feeding and Autoimmunity in Down's Syndrome Evaluation

Study) was established to investigate early feeding and the development of autoimmunity. Medical and detailed feeding data are collected by mothers from birth and includes both feeding in the hospital settings and at home. A study hypothesis is that babies with DS have difficulties with establishing breast feeding and are therefore introduced to formula feeds at an earlier age. This paper describes findings from the analysis of the feeding data collected between September 2014 and August 2017.

Methods:

FADES is an ongoing UK wide study recruiting babies with DS antenatally or in the first eight months of life. Exclusion criteria are babies born with a child protection plan, fostered or adopted, >8 months or parents do not speak English. Participants are recruited either by health professionals including neonatologists, community paediatricians and research nurses or via web recruitment through the Downs Syndrome Association, Downs Syndrome Scotland, and other websites and social media https://www.bristolbrc.nihr.ac.uk/our-research/nutrition-diet-and-lifestyle/childhood/fades-study-2/. A combined feeding and medical questionnaire is completed by families at recruitment (initial questionnaire), at six to eight months of life (7-month questionnaire) and then at 12 months (12-month questionnaire). Feeding questions are based on those from the Infant Feeding Survey (IFS) 2010 (15), medical questions are related to conditions associated with DS, hospital admissions and antibiotic usage. Mothers are able to provide free text answers to some questions. This paper presents data collected in the first three years of recruitment from 1st September 2014 to 31st August 2017 when the feasibility assessment was conducted.

Statistical Analysis: As a feasibility study, analysis of the questionnaires is descriptive as numbers are too small for statistical testing. Frequencies were derived and presented as percentages for categorical variables. For continuous data, means and standard deviations (SDs) were presented for data that were approximately normal, and medians and interquartile ranges (IQRs) for non-normal data. Analysis used STATA vs. 15.

Public involvement: The study design including recruitment and data collection methods were established following discussion with and involvement of the Downs Syndrome Association. Local members (all of whom were parents of a child with DS) advised on the wording and feasibility of the feeding and medical questionnaires.

Ethics approval for FADES was given by the National Research Ethics Service (NRES) Committee South West – Central Bristol 23rd April 2014 14/SW/0030 and it is an NIHR Portfolio study.

Results:

Seventy participants were recruited between the 1st September 2014 and the 31st August 2017. 87% (61 of 70) completed the initial feeding and medical questionnaire at a median age of 20 weeks (IQR 13, 29 weeks). Of these, approximately a quarter (n=15) were diagnosed antenatally with DS. Table 1 summarises maternal characteristics and birth details. Over half were born by normal vaginal delivery: median gestation, 38 weeks (IQR 37, 39 weeks), mean birthweight of 3kg (SD 0.5kg). Most babies were born in hospital units, three were home deliveries. Median hospital stay after birth was five days (IQR 3, 9 days).

Background Characteristics			
Maternal age (years) at time of completing initial questionnaire	20 to 24	8.2%	(5/61)
	25 to 29	9.8%	(6/61)
	30 to 34	24.6%	(15/61)
	35 to 39	37.7%	(23/61)
	40 or over	19.7%	(12/61)
Mother's marital status	Living together	27.9%	(17/61)
	Married or in a civil partnership	65.6%	(40/61)
	Single	4.9%	(3/61)
	Widowed, divorced, or separated	1.6%	(1/61)
Mother's ethnic group	Other	3.3%	(2/61)
	White British	86.9%	(53/61)
	White Irish	4.9%	(3/61)
	White Other	4.9%	(3/61)
Birth History			
First baby		31.2%	(19/61)
Prenatal diagnosis of DS		24.6%	(15/61)
Twin Birth		3.3%	(2/61)
Type of delivery	Normal Vaginal delivery	63.3%	(38/60)
	C-Section	28.3%	(17/60)
	Forceps	3.3%	(2/60)
	Ventouse	5.0%	(3/60)
Gestation (weeks)	Median 38 (IQR 37, 39)		
Pre-term 32-37 weeks		21.3%	(13/61)
Birthweight (kg)	Mean 3.0 (0.5 SD)		
Location of birth	At home	5.0%	(3/59)
	In hospital (consultant led)	49.2%	(29/59)
	In hospital (midwife led)	42.4%	(25/59)
	Birth centre (midwife led)	3.4%	(2/59)
Length of initial hospital stay (hours)	Median 120 (IQR 72, 216)		

Table 1: Maternal characteristics and birth details

Footnote: DS (Down's syndrome), IQR (inter quartile range), SD (standard deviation), C-section (Caesarean Section)

Over half (56%) were admitted into a special care baby unit (SCBU) with almost a third of these (29%) primarily due to poor feeding. Half of the babies for whom data were available, required naso-gastric (NG) tube feeding as shown in Table 2. All admitted to SCBU, were

NG tube fed. Around 40%, primarily required NG tube feeds in SCBU due to feeding issues, the remainder due to medical co-morbidities (37% with multiple medical indications). NG tube feeds were mostly expressed breastmilk or a mixture of expressed milk and infant formula. Just over 60% required NG tube feeds for less than two weeks.

SCBU Admission			
Admitted to SCBU		55.7%	(34/61)
Admitted to SCBU due to problems with feeding		29.4%	(10/34)
Admitted to SCBU for any other reason*		70.6%	(24/34)
Hypoxia / respiratory distress / PPHN		50.0%	(17/34)
Jaundice		20.6%	(7/34)
Cardiac / cardiac monitoring		11.8%	(4/34)
Infection		11.8%	(4/34)
Prematurity		8.8%	(3/34)
Polycythaemia		5.9%	(2/34)
Other		20.6%	(7/34)
Length of SCBU stay (weeks)		Median 2 (IQR 2, 4)	
Feeding in SCBU and NG tube Feeds			
SCBU admission affected ability of mother to feed baby as she would have liked		67.7 %	(23/34)
Shown how to express milk in SCBU		85.3 %	(29/34)
Felt supported to express milk in SCBU		90.0 %	(27/30)
Had NG tube feeds		100 %	(31/31*)
Required NG tube feeds due to problems with feeding		38.7 %	(12/31)
Medical reason for NG tube feeds**	Prematurity	10.5 %	(2/19)
	Dehydration / hydration	10.5 %	(2/19)
	Ventilation	10.5 %	(2/19)
	Respiratory problems	42.1 %	(8/19)
	Jaundice / polycythaemia	21.1 %	(4/19)
	Vomiting or surgical abdomen	21.1 %	(4/19)
Length of time NG tube fed	< 3 days	16.1 %	(5/31)
	> 3 to 7 days	19.4 %	(6/31)
	> 1 to 2 weeks	25.8 %	(8/31)
	> 2 to 4 weeks	19.4 %	(6/31)
	> 1 to 2 months	16.1 %	(5/31)
	> 2months	3.2 %	(1/31)
Type of NG tube feeds given	Only expressed breast milk	32.3 %	(10/31)
	Only infant formula	6.5 %	(2/31)
	Expressed breast milk and infant formula	61.3 %	(19/31)
Feeds stopped and IV fluids given		32.4 %	(11/34)
Length of time on IV fluids	< 3 days	22.2 %	(2/9)
	> 3 to 7 days	44.4 %	(4/9)
	> 7 days to 1 month	33.3 %	(3/9)

Table 2: Feeding in SCBU (special care baby unit) and NG (naso-gastric) tube feeds

Footnote: IV fluids (Intra- venous fluids), PPHN (persistent pulmonary hypertension of the newborn),
*Due to an issue with branching of the questions at least 31 babies were NG tube fed but there may have been more. Where they were branched away, people have been counted as missing, so the denominator is 31.
**Coded from open response

Of the mothers receiving an antenatal diagnosis for their baby, 87% were told about problems relating to feeding but only 20% received any specific antenatal advice about breastfeeding a baby with DS. Most mothers initially breastfed their baby, with 78% having skin to skin contact within 24 hours of birth (Table 3). Feeding problems that were experienced in the hospital or birthing centre by mothers, included those commonly associated with babies with DS such as poor latch and lethargy. Although hypotonia is one of the explanations frequently given as a cause for feeding difficulties, only one parent described this feature. Mothers provided responses to an open question regarding feeding their baby in the hospital, birth centre or unit as illustrated in the quotes in Table 4.

First Feeds			
Ever breastfed or received expressed breast milk		90.2 %	(55/61)
Had skin to skin contact within 24hrs of birth		78.3 %	(47/60)
Maternal health problems after birth that affected feeding		6.6 %	(4/61)
Received help with breastfeeding within first few days		66.7 %	(40/60)
How soon after birth was baby put to the breast	within a few minutes	25.5 %	(14/55)
	<30 min	30.9 %	(17/55)
	30 min to 1 hr	16.4 %	(9/55)
	>1 hr to 8 hrs	5.5 %	(3/55)
	>8 hrs to 24 hrs	5.5 %	(3/55)
	> 24 hrs later	16.4 %	(9/55)
Experienced problems when feeding their baby in the hospital, birth centre or unit		77.5 %	(45/58*)
Common problems with feeding**	Poor latch	44.4 %	(20/45)
	Medical issue	31.1 %	(14/45)
	Jaundice	31.1 %	(14/45)
	Tired / lethargic	28.9 %	(13/45)
	Maternal reason	8.9 %	(4/45)
	Tongue size/ position	6.7 %	(3/45)
	Low tone	2.2 %	(1/45)
Reported that they received enough help with feeding in hospital / birth centre		82.8 %	(48/58)
General Feeding and feeding after discharge from hospital / birth centre			
Problems with feeding baby after discharge from hospital / birth centre		53.6%	(30/56)
Problems with feeding after discharge**			
	Lethargy	21.3%	(13/61)
	Poor weight gain / weight loss	16.4%	(10/61)
	Low tone	1.6%	(1/61)
	Latch	8.2%	(5/61)
	Medical	4.9%	(3/61)
	Jaundice	4.9%	(3/61)
	Reflux	4.9%	(3/61)
Received help or information with feeding problems after discharge		84.4%	(27/32***)

Table 3: First feeds and feeding after discharge

Footnote:* Three babies were home births ** These problems were coded from open responses
***This denominator comes from the 30 participants who experienced problems with feeding after discharge from hospital and two who experienced problems with feeding after their home birth.

Question from initial questionnaire	**'Were there any problems feeding your baby while you were in the hospital, birth centre or unit? What problems were there?'**
Quotes	*"X would not take anything from the breast and was very sleepy so had an NG tube put in."* *"A feeding tube was inserted straight away, which prevented me from breast feeding. It also prevented her from becoming hungry enough to feed from me"* *"baby continually pushing tongue out and could not latch on. Decided to try the bottle which she took immediately so did not try breast again and was not questioned by staff"*
Question from Initial, 7 month and 12 month questionnaire	**'Have you stopped breastfeeding (no longer give your baby any expressed milk or put your baby to your breast)? What were your reasons for stopping?'**
Quotes	*"Significant weight loss in early days, poor latch, inadequate milk being taken by baby, readmission to hospital for tube feeding, introduction of bottle feeding in hospital, milk supply subsequently drying up due to baby being put on bottle and use of pumps further made milk supply deteriorate."* *"Baby fell asleep too much at the breast to feed properly. It was too time consuming and stressful to keep expressing."*
Question from initial, 7-month and 12-month questionnaires	**"What would have helped you breastfeed longer?"**
Quotes	*"Knowing as I do now that it's common to have feeding problems with Down syndrome. More specific breastfeeding support."* (from initial questionnaire) *"I feel I was forced to give Child's name a bottle when she was only a day old as the midwife was unwilling to entertain my concerns about the bottle meaning that she would never take the breast. I had wanted to give the milk by syringe or cup to give her a chance to keep trying the breast, but I was shot down and ridiculed."* (from 7-month questionnaire) *"I just became too sick, unwell but at the same time I fed longer than I thought I would. Thanks to the support I received."* (from 12-month questionnaire) *"She lost 6% of her birth weight by day 9 and the NICU home midwife suggested we move onto top up.*

	I think that was the pinch point. If I had said no, let's try harder to feed from the breast it might have established itself. But she had just been discharged from hospital and I was so reluctant to go back. You really have the threat of readmission hanging over you… I would have loved to feed her myself. It is my biggest sadness but there were too many other variables at play. I am pleased I was able to exclusively breast feed her though for well over 4 months." (from 12-month questionnaire)

Table 4: Quotes from free text boxes in initial, 7 month and 12 month questionnaire

Of the 61 mother/baby dyads, 64% continued some breastfeeding for over six weeks (Table 5) (including babies who received mixed infant formula and breastmilk feeds). Over the age of six months, this decreased to 54% still breastfeeding in part. These percentages are higher than in the general population, levels reported in the Infant Feeding Survey (IFS) 2010 (55% and 34% respectively) (15). The prevalence of exclusive breastfeeding in the study population at six weeks was 21% compared to 23% in the general population in the IFS 2010 (15). By six months of age, less than 4% of participants were exclusively breast fed (2/54). This compares to 1% of general population. Using data from the initial and 7-month questionnaires, the median age at which some formula milk was introduced in the whole cohort was five days (IQR 1, 21 days). Formula feeds were introduced by 52% of mothers within a week in the IFS 2010 and 75% by 6 weeks.

Types of feeds / Stopping breastfeeding		
Age stopped breastfeeding*		
6 weeks or less	40.7%	(11/27**)
> 6 weeks to 4 months	25.9%	(7/27)
> 4 months to 6 months	11.1%	(3/27)
> 6 months	22.2%	(6/27)
Age started formula feeds		
6 weeks or less	77.2%	(44/57***)
> 6 weeks to 4 months	5.3%	(3/57)
> 4 months to 6 months	8.8%	(5/57)
> 6 months	8.8%	(5/57)
Age when given a non – milk drink**** (weeks)	Median 26 (IQR 20, 28)	
Age at which first given cow's milk (weeks)	Median 44 (IQR 28, 36)	

Stopping breastfeeding and problems with feeding	Initial Questionnaire	7 month Questionnaire	12 month Questionnaire
Maternal opinion on how long they breastfed			
Breastfed for as long as they intended	37.8% (14/37)	17.4% (4/23)	20.0% (4/20)
Breastfed for longer than they intended	8.1% (3/37)	13.0% (3/23)	15.0% (3/20)
Would have liked to breastfeed longer.	54.1% (20/37)	69.6% (16/23)	65.0% (13/20)
Reasons for stopping breastfeeding			
Inadequate breastmilk supply	30% (6/20)	13.0% (7/54)	5.0% (2/40)
Problems expressing milk	25% (5/20)	5.6% (3/54)	10.0% (4/40)
Excessive time expressing milk	25% (5/20)	1.9% (1/54)	5.0% (2/40)
Baby losing weight	20% (4/20)	3.7% (2/54)	5.0% (2/40)
Maternal medical problem	15% (3/20)	3.7% (2/54)	2.5% (1/40)
Lethargy	5% (1/20)	1.9% (1/54)	
Weaning by choice	n/a	7.4% (4/54)	7.5% (3/40)
Other		5.6% (3/54)	10.0% (4/40)

Table 5: Stopping Breastfeeding

*Footnote: *including using expressed breastmilk and mixed feeding and/or were introduced to other types of milk feeds or drinks. **this denominator is the number of women who had stopped breastfeeding by the data cut off date for data analysis. Some babies would still have been receiving breastmilk at the cut-off date for data analysis. Some would also have been still mixed feeding both breastmilk and formula ****Non-milk drinks included any drink other than milk including water (which would be fine) and juices which would not be recommended.*

Just over half of the participants had problems associated with feeding after discharge from hospital (Table 3). The most common problems were lethargy or faltering growth. Three mothers mentioned their babies being readmitted to hospital with poor feeding. Less than three-quarters, 72% (34/47) had the correct ‘DS insert’ in their Red book (the personal child health record that is given to every baby). The ‘DS insert’ contains the appropriate growth charts reflecting a tendency to ‘normal’, slower growth trajectory in this condition compared to non-trisomy babies (16).

Over half of the mothers said that they would have liked to have breastfed for longer. Reasons for stopping breastfeeding included inadequate breastmilk supply, issues with expressing breast milk and their babies having faltering growth. The quotes in Table 4 illustrate the reasons mothers gave for stopping breastfeeding.

Mothers were asked “What would have helped you breastfeed longer?” the answers included not introducing bottles as early, not needing to express, being at home and having more specific support. Quotes from the initial, 7-month and 12-month questionnaires in response to this question are given in Table 4. Some mothers also used this question to explain that they did breastfeed.

Discussion:

We have shown that exclusive breastfeeding amongst the babies with DS at six months is comparable to the general population (4% vs 1%). Apart from exclusive breastfeeding at six weeks when prevalence was similar (21% of babies with DS versus 23% in the general population), breastfeeding (exclusive or combination feeding) amongst the study participants was higher at all time points than levels reported in the general population (15). This was surprising and does not support the hypothesis that hypotonia and oro-motor issues associated with DS significantly alters ability to breastfeed. This is an important and encouraging message for mothers and should inspire midwives and health professionals to support breast feeding. These findings suggest that the frequently heard mantra, that babies with DS probably will not breastfeed successfully, needs to be changed.

Formula was introduced very early at a median of five days with 77% having started by the age of six weeks. Overall, over half of the mothers were still breastfeeding beyond the age of six months (including babies who combination fed with breastmilk and infant formula) which is a very positive message for families. This is higher than the 34% at six months within the general population. Due to the wording of the questionnaire, it was not possible to distinguish between those who directly breastfed or those who gave expressed breastmilk, and this would be useful to include in future questionnaires.

Over half of FADES babies were admitted to SCBU, all being NG tube fed. In around 40%, issues with feeding were responsible for NG placement and for most of these participants, this was also the reason for SCBU admission. Almost 70% of the mothers said that having their baby in SCBU had affected their ability to feed the way they would have liked. This is possibly open to intervention as some admissions might be prevented with more specialised/tailored support on the postnatal wards. Some hospitals will only have one or two babies born a year with DS, possibly leading to automatic SCBU admissions with increased levels of anxiety around potential complications and associated conditions. In terms of oro-motor skill development, it is important that babies have the chance to feed orally early on. This is postulated to be important for the development of oral skills, tolerance of tastes and textures and is also important for social development (17). Most babies in our cohort required NG tube feeds for less than two weeks but a third also required feeds to be stopped altogether at some point and were put onto intravenous fluids.

NG tube feeding was required for some babies due to dehydration, jaundice, polycythaemia and vomiting. Although classified as a 'medical' reason, inability to feed may have contributed or caused these issues. Other 'medical' reasons, were are all standard causes for any neonate to receive NG tube feeds including prematurity, ventilation or surgical abdomen. Prevalence of NG tube feeding in the general population and in the typical DS population are poorly reported. A third of those NG fed babies continued to receive exclusively expressed breastmilk. Many of the babies were fed using expressed breastmilk either for NG tube feeds or for top up feeds via alternative feeding methods including bottle.

Lethargy was the most commonly reported problem with feeding after discharge with far fewer citing poor latch than during the initial admission. Importantly 16% of the mothers said that poor weight gain or weight loss was an issue. It is of concern that over a quarter of the mothers reported that they were not given the correct 'DS insert' in their Personal Child Health Record ('Red' book) (16). Healthy babies with DS gain weight more slowly than other babies and it is important to account for this when assessing feeding and growth. If a baby with DS is plotted on a standard growth chart they will appear to be failing to thrive and a mother who is successfully feeding her baby, may be told that she needs to supplement feeds, start formula feeds if she is breastfeeding or even that her baby needs admission to hospital.

The higher levels of breastfeeding in the study compared to the general population may in part, be due to selection bias. Mothers who have chosen to take part in the study may already have a specific interest in infant feeding. In the UK, higher breastfeeding frequency is described in mothers over 30 years of age (87%) (15) which may also explain the higher level of initial breastfeeding in FADES. The karyotype for the babies in the cohort was not requested which might be considered a weakness of the study. FADES potentially might include children with mosaic Down's syndrome who can be phenotypically milder although this is rare: Only one to three percent of DS children have Mosaicism (18).

Reasons for stopping breastfeeding were similar to the IFS 2010 (15) with inadequate breastmilk supply and faltering growth being common. However, a large proportion mentioned issues surrounding expressing milk. This highlights the need for mothers who are expressing to receive tailored support. Mothers were asked "What would have helped you breastfeed longer" the responses indicated that mothers understandably wanted 'normality', they wanted their babies to be well, to not require bottle or expressed milk and to be at home. Although it is not possible to change these factors for many, every effort should be made to listen to maternal wishes and assist where possible. Some mothers used this questionnaire to voice their frustration at alternative feeding methods being introduced 'too early' or 'against their wishes'.

It is a strength of the study that the families recruited were representative of the general population of children with DS, with similar numbers of children having associated conditions including cardiac abnormalities as reported in other studies (19). The eligibility criteria were broad and did not exclude any medical conditions. A further strength is that the study was UK wide reducing selection bias. Those who could not speak English were excluded and this may have had altered feeding results with cultural differences in early feeding (20). Translating all study documentation however was not possible for the multiple languages now represented in UK population.

These results raise some important questions and highlight potential opportunities for interventions in relation to feeding support for mothers of babies with DS. Any advice given to mothers on feeding a baby with DS based on this study should include the message that babies with DS can be exclusively breastfed or receive a combination of breast and formula feeds. However, some may need to include expressed breastmilk and alternative feeding methods. Providing mothers with access to tailored support and advice specifically around expressing should be included, as should information on NG tube feeding.

Conclusion:

It is clear that some babies with DS can breastfeed exclusively for six months as per WHO guidelines. This may require significant perseverance from the mother and supportive professionals, as establishing breastfeeding can be challenging. Oro-motor difficulties and significant medical needs may underlie some challenges, but overall, mothers who wish to breastfeed should be encouraged and supported to do so as success is possible.

Boxes – What is already known on this topic (bullet points)

- Babies with DS have anatomical and physiological features that may affect their ability to feed but this is phenotypically variable.
- Babies with DS have associated medical conditions including congenital heart disease and gastro-intestinal abnormalities which may impact on early feeding.
- Prevalence of NG Tube feeding in babies with DS has previously been reported as up to 40%.

What this study adds

- Breastfeeding prevalence amongst babies with DS are equivalent to the general population at 6 months.
- Babies with DS can receive exclusive breast-milk feeds for over 6 months.
- Early and extra post-natal support for breast feeding may be beneficial.
- At least half of babies with DS in this UK wide cohort study receive nasogastric feeds.

How this Study might affect research, practice or policy

- This study seeks to promote an increase in tailored feeding support for mother's of babies with DS.
- Key findings from this study may contribute to positive changes in breastfeeding advice and support for mother's of babies with DS.
- The high prevalence of babies receiving naso-gastric tube feeds warrants further research and potentially change in policy within neonatal units.

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Competing interests: No competing interests

Authors Contribution: Georgina M.G. Williams was the chief investigator and PhD student, wrote the protocol, completed the data collection, data analysis and drafts of the manuscript. Sam Leary was the lead statistician on the study and PhD supervisor. She contributed to the protocol and study design, data analysis and draft manuscripts of the paper. Sofia Leadbetter provided the administrative support and coordination for the study, she was involved in participant recruitment and data collection. Stu Toms contributed to the study design, online questionnaires and managed the study database. Georgina Mortimer contributed to the data collection and coordinates sample collection for the FADES study. Tim Scorrer recruited participants for the study and reviewed draft manuscripts of the paper. Kathleen Gillespie (PhD supervisor) contributed to the study protocol, study design and reviewed draft manuscripts of the article. Julian Hamilton Shield (PhD supervisor) contributed to the study protocol, study design and reviewed draft manuscripts of the articles.

Data Sharing: Data sets may only be available by individual request to the Corresponding Author.

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Establishing breast feeding in Infants with Down syndrome: the FADES cohort experience

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Establishing breast feeding in infants with Down syndrome: the FADES cohort experience

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Abstract:

Objective: To describe breast feeding prevalence, and maternal experience in infants with Trisomy 21.

Design: Longitudinal cohort study

Setting: Participants from UK recruited through websites, social media and local collaborators: neonatologists, community paediatricians and research nurses.

Subjects: Infants under the age of 8 months with Down syndrome (DS) recruited to the FADES (Feeding and Autoimmunity in Down Syndrome Evaluation Study) between the 1st September 2014 to 31st August 2017. Seventy participants: median age 20 weeks (Interquartile range (IQR) 13, 29 weeks) at initial questionnaire.

Main outcome measure: Breastfeeding prevalence at 6 weeks and 6 months amongst infants with DS.

Results: The prevalence of exclusive breastfeeding amongst study participants was similar to the general population (13/61 21% vs 23% at 6 weeks, 2/54 4% vs 1% at 6 months). However, the prevalence of breastfeeding (exclusive or combination feeding) amongst the study participants was higher than the general population (39/61 64% vs 55% at 6 weeks, 32/59 54% vs 34% at 6 months).

Conclusion: Although there may be challenges in establishing breastfeeding in infants with DS, our data suggest that exclusive breastfeeding is possible for some, and the prevalence of breastfeeding is comparable to the prevalence in the general population.

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Keywords: Down Syndrome, Trisomy 21, Feeding, Breast-feeding,

Background

Down syndrome (DS) is caused by trisomy of chromosome 21. DS is usually diagnosed antenatally or in the first few days of life by recognition of salient features (1). A number of associated conditions including congenital heart disease and gastrointestinal complications can cause additional challenges during the neonatal period.

Current World Health Organisation (WHO) recommendations are that infants should be exclusively breastfed until 6 months (5), this is based on the health benefits for mother and baby. Prolonged exclusive breastfeeding is possibly protective against some autoimmune conditions including type 1 diabetes and coeliac disease for which children with DS are at increased risk (6,7,8). Furthermore, there is evidence that breastfeeding exclusively or combined feeding to a lesser but significant extent, enhances immunity and is protective against otitis media and respiratory tract infections (9) both being more prevalent in children with DS (10).

Infants with DS may have oral, anatomical and physiological abnormalities affecting their ability to feed normally: as with other features of DS there is phenotypic variability. To breastfeed effectively, a tight oral/nipple seal needs to be induced with the tongue making a groove and the lips sealing around the nipple. For a baby with DS, the flattened shape of the tongue and low tone in the oral structures means that establishing breastfeeding may be challenging. (2,3). Lewis et al reported that 40% of DS infants had been naso-gastric (NG) tube fed during the neonatal period illustrating some of the issues with feeding (4).

Many countries have registers which provide data on people with DS. These have facilitated retrospective studies providing statistics on for example: birth and death rates and congenital anomalies. However longitudinal birth cohort studies of infants with DS in the UK are rare (11,12,13,14). The FADES (Feeding and Autoimmunity in Down Syndrome Evaluation Study) was established to investigate early feeding and the development of autoimmunity. Medical and detailed feeding data are collected by mothers from birth and includes both feeding in the hospital settings and at home. A study hypothesis is that infants with DS have difficulties with establishing breast feeding and are therefore introduced to formula feeds at an earlier age. The aim of this paper is to describe breastfeeding prevalence and experiences among infants with DS and their mothers, in the first six months of life. This paper describes findings from the analysis of the feeding data collected between September 2014 and August 2017, to explore this and compare to breastfeeding prevalence in the general population.

Methods:

FADES is an ongoing UK wide study recruiting infants with DS antenatally or in the first eight months of life. Exclusion criteria are infants born with a child protection plan, fostered or adopted, >8 months or parents do not speak English. Participants are recruited either by health professionals including neonatologists, community paediatricians and research nurses or via web recruitment through the Downs Syndrome Association, Downs Syndrome Scotland, and other websites and social media https://www.bristolbrc.nihr.ac.uk/our-research/nutrition-diet-and-lifestyle/childhood/fades-study-2/. A combined feeding and medical questionnaire is completed by families at recruitment (initial questionnaire), at six to eight months of life (7-month questionnaire) and then at 12 months (12-month questionnaire). Feeding questions are based on those from the Infant Feeding Survey (IFS) 2010 (15), medical questions are related to conditions associated with DS, hospital admissions and antibiotic usage. Mothers are able to provide free text answers to some questions and quotes from these have been used to illustrate key points. A full qualitative study and analysis has not been completed as part of this feasibility study. This paper presents data collected in the first three years of recruitment from 1st September 2014 to 31st August 2017 when the feasibility assessment was conducted.

Statistical Analysis: As a feasibility study, analysis of the questionnaires is descriptive as there is not enough power to statistically test for associations. Frequencies were derived and presented as percentages for categorical variables. For continuous data, means and standard deviations (SDs) were presented for data that were approximately normal, and medians and interquartile ranges (IQRs) for non-normal data. Analysis used STATA vs. 15. Comparisons are made with the general population from the results reported by the IFS 2010 (15).

Public involvement: The study design including recruitment and data collection methods were established following discussion with and involvement of the Downs Syndrome Association. Local members (all of whom were parents of a child with DS) advised on the wording and feasibility of the feeding and medical questionnaires.

Ethics approval for FADES was given by the National Research Ethics Service (NRES) Committee South West – Central Bristol 23rd April 2014 14/SW/0030 and it is an NIHR Portfolio study.

Results:

Seventy participants were recruited between the 1st September 2014 and the 31st August 2017. 61 out of the 70 participants (87%) completed the initial feeding and medical questionnaire at a median age of 20 weeks (IQR 13, 29 weeks). Of these, approximately a quarter (n=15) were diagnosed antenatally with DS. Table 1 summarises maternal characteristics and birth details. Over half were born by normal vaginal delivery: median gestation, 38 weeks (IQR 37, 39 weeks), mean birthweight of 3kg (SD 0.5kg). Most infants were born in hospital units, three were home deliveries. Median hospital stay after birth was five days (IQR 3, 9 days).

Background Characteristics		
Maternal age (years) at time of completing initial questionnaire	20 to 24	5/61 (8.2%)
	25 to 29	6/61 (9.8%)
	30 to 34	15/61 (24.6%)
	35 to 39	23/61 (37.7%)
	40 or over	12/61 (19.7%)
Mother's marital status	Living together	17/61 (27.9%)
	Married or in a civil partnership	40/61 (65.6%)
	Single	3/61 (4.9%)
	Widowed, divorced, or separated	1/61 (1.6%)
Mother's ethnic group	Other	2/61 (3.3%)
	White British	53/61 (86.9%)
	White Irish	3/61 (4.9%)
	White Other	3/61 (4.9%)
Birth History		
First baby		19/61 (31.2%)
Prenatal diagnosis of DS		15/61 (24.6%)
Twin Birth		2/61 (3.3%)
Type of delivery	Normal Vaginal delivery	38/60 (63.3%)
	C-Section	17/60 (28.3%)
	Forceps	2/60 (3.3%)
	Ventouse	3/60 (5.0%)
Gestation (weeks)	Median 38 (IQR 37, 39)	
Pre-term 32-37 weeks		13/61 (21.3%)
Birthweight (kg)	Mean 3.0 (0.5 SD)	
Location of birth	At home	3/59 (5.0%)
	In hospital (consultant led)	29/59 (49.2%)
	In hospital (midwife led)	25/59 (42.4%)
	Birth centre (midwife led)	2/59 (3.4%)
Length of initial hospital stay (hours)	Median 120 (IQR 72, 216)	

Table 1: Maternal characteristics and birth details

Footnote: DS (Down syndrome), IQR (inter quartile range), SD (standard deviation), C-section (Caesarean Section)

Over half (34/61, 56%) were admitted into a special care baby unit (SCBU) with almost a third of these (10/34, 29%) primarily due to poor feeding. Half of the infants for whom data were available, required NG tube feeding as shown in Table 2. All admitted to SCBU, were NG tube fed. Of the 31 infants who were fed via NG tube, 12/31 (40%), primarily required

NG tube feeds in SCBU due to feeding issues, the remainder due to medical co-morbidities (37% with multiple medical indications). NG tube feeds were mostly expressed breastmilk or a mixture of expressed milk and infant formula. NG tube feeds were required in 19/31 (60%) participants for less than two weeks.

SCBU Admission		
Admitted to SCBU		34/61 (55.7%)
Admitted to SCBU due to problems with feeding		10/34 (29.4%)
Admitted to SCBU for any other reason*		24/34 (70.6%)
Hypoxia / respiratory distress / PPHN		17/34 (50.0%)
Jaundice		7/34 (20.6%)
Cardiac / cardiac monitoring		4/34 (11.8%)
Infection		4/34 (11.8%)
Prematurity		3/34 (8.8%)
Polycythaemia		2/34 (5.9%)
Other		7/34 (20.6%)
Length of SCBU stay (weeks)		Median 2 (IQR 2, 4)
Feeding in SCBU and NG tube Feeds		
SCBU admission affected ability of mother to feed baby as she would have liked		23/34 (67.7 %)
Shown how to express milk in SCBU		29/34 (85.3 %)
Felt supported to express milk in SCBU		27/30 (90.0 %)
Had NG tube feeds		31/31* (100 %)
Required NG tube feeds due to problems with feeding		12/31 (38.7 %)
Medical reason for NG tube feeds**	Prematurity	2/19 (10.5 %)
	Dehydration / hydration	2/19 (10.5 %)
	Ventilation	2/19 (10.5 %)
	Respiratory problems	8/19 (42.1 %)
	Jaundice / polycythaemia	4/19 (21.1 %)
	Vomiting or surgical abdomen	4/19 (21.1 %)
Length of time NG tube fed	< 3 days	5/31 (16.1 %)
	> 3 to 7 days	6/31 (19.4 %)
	> 1 to 2 weeks	8/31 (25.8 %)
	> 2 to 4 weeks	6/31 (19.4 %)
	> 1 to 2 months	5/31 (16.1 %)
	> 2months	1/31 (3.2 %)
Type of NG tube feeds given	Only expressed breast milk	10/31 (32.3 %)
	Only infant formula	2/31 (6.5 %)
	Expressed breast milk and infant formula	19/31 (61.3 %)
Feeds stopped and IV fluids given		11/34 (32.4 %)
Length of time on IV fluids	< 3 days	2/9 (22.2 %)
	> 3 to 7 days	4/9 (44.4 %)
	> 7 days to 1 month	3/9 (33.3 %)

Table 2: Feeding in SCBU (special care baby unit) and NG (naso-gastric) tube feeds

Footnote: IV fluids (Intra- venous fluids), PPHN (persistent pulmonary hypertension of the newborn),
*Due to an issue with branching of the questions at least 31 infants were NG tube fed but there may have been more. Where they were branched away, people have been counted as missing, so the denominator is 31.
**Coded from open response

Of the mothers receiving an antenatal diagnosis for their baby, 13/15 (87%) were told about problems relating to feeding but only three (3/15, (20%)) received any specific antenatal advice about breastfeeding a baby with DS. Most mothers initially breastfed their baby, with 47/60 (78%) having skin to skin contact within 24 hours of birth (Table 3). Feeding problems that were experienced in the hospital or birthing centre by mothers, included those commonly associated with infants with DS such as poor latch and lethargy. Although hypotonia is one of the explanations frequently given as a cause for feeding difficulties, only one parent described this feature. Mothers provided responses to an open question regarding feeding their baby in the hospital, birth centre or unit as illustrated in the quotes in Table 4.

First Feeds		
Ever breastfed or received expressed breast milk		55/61 (90.2 %)
Had skin to skin contact within 24hrs of birth		47/60 (78.3 %)
Maternal health problems after birth that affected feeding		4/61 (6.6 %)
Received help with breastfeeding within first few days		40/60 (66.7 %)
How soon after birth was baby put to the breast	within a few minutes	14/55 (25.5 %)
	<30 min	17/55 (30.9 %)
	30 min to 1 hr	9/55 (16.4 %)
	>1 hr to 8 hrs	3/55 (5.5 %)
	>8 hrs to 24 hrs	3/55 (5.5 %)
	> 24 hrs later	9/55 (16.4 %)
Experienced problems when feeding their baby in the hospital, birth centre or unit		45/58* (77.5 %)
Common problems with feeding**	Poor latch	20/45 (44.4 %)
	Medical issue	14/45 (31.1 %)
	Jaundice	14/45 (31.1 %)
	Tired / lethargic	13/45 (28.9 %)
	Maternal reason	4/45 (8.9 %)
	Tongue size/ position	3/45 (6.7 %)
	Low tone	1/45 (2.2 %)
Reported that they received enough help with feeding in hospital / birth centre		48/58 (82.8 %)
General Feeding and feeding after discharge from hospital / birth centre		
Problems with feeding baby after discharge from hospital / birth centre		30/56 (53.6%)
Problems with feeding after discharge**		
	Lethargy	13/61 (21.3%)
	Poor weight gain / weight loss	10/61 (16.4%)
	Low tone	1/61 (1.6%)
	Latch	5/61 (8.2%)
	Medical	3/61 (4.9%)
	Jaundice	3/61 (4.9%)
	Reflux	3/61 (4.9%)
Received help or information with feeding problems after discharge		27/32*** (84.4%)

Table 3: First feeds and feeding after discharge

Footnote:* Three infants were home births ** These problems were coded from open responses
***This denominator comes from the 30 participants who experienced problems with feeding after discharge from hospital and two who experienced problems with feeding after their home birth.

Question from initial questionnaire	**'Were there any problems feeding your baby while you were in the hospital, birth centre or unit? What problems were there?'**
Quotes	*"X would not take anything from the breast and was very sleepy so had an NG tube put in."* *"A feeding tube was inserted straight away, which prevented me from breast feeding. It also prevented her from becoming hungry enough to feed from me"* *"baby continually pushing tongue out and could not latch on. Decided to try the bottle which she took immediately so did not try breast again and was not questioned by staff"*
Question from Initial, 7 month and 12 month questionnaire	**'Have you stopped breastfeeding (no longer give your baby any expressed milk or put your baby to your breast)? What were your reasons for stopping?'**
Quotes	*"Significant weight loss in early days, poor latch, inadequate milk being taken by baby, readmission to hospital for tube feeding, introduction of bottle feeding in hospital, milk supply subsequently drying up due to baby being put on bottle and use of pumps further made milk supply deteriorate."* *"Baby fell asleep too much at the breast to feed properly. It was too time consuming and stressful to keep expressing."*
Question from initial, 7-month and 12-month questionnaires	**"What would have helped you breastfeed longer?"**
Quotes	*"Knowing as I do now that it's common to have feeding problems with Down syndrome. More specific breastfeeding support." (from initial questionnaire)* *"I feel I was forced to give Child's name a bottle when she was only a day old as the midwife was unwilling to entertain my concerns about the bottle meaning that she would never take the breast. I had wanted to give the milk by syringe or cup to give her a chance to keep trying the breast, but I was shot down and ridiculed." (from 7-month questionnaire)* *"I just became too sick, unwell but at the same time I fed longer than I thought I would. Thanks to the support I received." (from 12-month questionnaire)* *"She lost 6% of her birth weight by day 9 and the NICU home midwife suggested we move onto top up. I think that was the pinch point. If I had said no, let's try harder to feed from the breast it might have established itself. But*

	she had just been discharged from hospital and I was so reluctant to go back. You really have the threat of readmission hanging over you… I would have loved to feed her myself. It is my biggest sadness but there were too many other variables at play. I am pleased I was able to exclusively breast feed her though for well over 4 months.” (from 12-month questionnaire)

Table 4: Quotes from free text boxes in initial, 7 month and 12 month questionnaire

Of the 61 mother/baby dyads, 39 (64%) continued some breastfeeding for over six weeks (Table 5) (including infants who received mixed infant formula and breastmilk feeds). Over the age of six months, this decreased to 32 (32/59 (54%)) still breastfeeding in part. These percentages are higher than in the general population, levels reported in the Infant Feeding Survey (IFS) 2010 (55% and 34% respectively) (15). The prevalence of exclusive breastfeeding in the study population at six weeks was 13/61 (21%) compared to 23% in the general population in the IFS 2010 (15). By six months of age, two (2/54 (4%)) participants were exclusively breast fed. This compares to 1% of general population. Using data from the initial and 7-month questionnaires, the median age at which some formula milk was introduced in the whole cohort was five days (IQR 1, 21 days). Formula feeds were introduced by 52% of mothers within a week in the IFS 2010 and 75% by 6 weeks.

Types of feeds / Stopping breastfeeding			
Age stopped breastfeeding*			
6 weeks or less	11/27** (40.7%)		
> 6 weeks to 4 months	7/27 (25.9%)		
> 4 months to 6 months	3/27 (11.1%)		
> 6 months	6/27 (22.2%)		
Age started formula feeds			
6 weeks or less	44/57*** (77.2%)		
> 6 weeks to 4 months	3/57 (5.3%)		
> 4 months to 6 months	5/57 (8.8%)		
> 6 months	5/57 (8.8%)		
Age when given a non – milk drink**** (weeks)	Median 26 (IQR 20, 28)		
Age at which first given cow's milk (weeks)	Median 44 (IQR 28, 48)		
Stopping breastfeeding and problems with feeding	Initial Questionnaire	7 month Questionnaire	12 month Questionnaire
Maternal opinion on how long they breastfed			
Breastfed for as long as they intended	14/37(37.8%)	4/23 (17.4%)	4/20 (20.0%)
Breastfed for longer than they intended	3/37 (8.1%)	3/23 (13.0%)	3/20 (15.0%)
Would have liked to breastfeed longer.	20/37 (54.1%)	16/23 (69.6%)	13/20 (65.0%)
Reasons for stopping breastfeeding			
Inadequate breastmilk supply	6/20 (30%)	7/54 (13.0%)	2/40 (5.0%)
Problems expressing milk	5/20 (25%)	3/54 (5.6%)	4/40 (10.0%)
Excessive time expressing milk	5/20 (25%)	1/54 (1.9%)	2/40 (5.0%)
Baby losing weight	4/20 (20%)	2/54 (3.7%)	2/40 (5.0%)
Maternal medical problem	3/20 (15%)	2/54 (3.7%)	1/40 (2.5%)
Lethargy	1/20 (5%)	1/54 (1.9%)	
Weaning by choice	n/a	4/54 (7.4%)	3/40 (7.5%)
Other		3/54 (5.6%)	4/40 (10.0%)

Table 5: Stopping Breastfeeding

*Footnote: *including using expressed breastmilk and mixed feeding and/or were introduced to other types of milk feeds or drinks. **this denominator is the number of women who had stopped breastfeeding by the data cut off date for data analysis. Some infants would still have been receiving breastmilk at the cut-off date for data analysis. Some would also have been still mixed feeding both breastmilk and formula ****Non-milk drinks included any drink other than milk including water (which would be fine) and juices which would not be recommended.*

Just over half of the participants had problems associated with feeding after discharge from hospital (Table 3). The most common problems were lethargy or faltering growth. Three mothers mentioned their infants being readmitted to hospital with poor feeding. Less than three-quarters, 34/47 (72%) had the correct 'DS insert' in their Red book (the personal child health record that is given to every baby). The 'DS insert' contains the appropriate growth charts reflecting a tendency to 'normal', slower growth trajectory in this condition compared to non-trisomy infants (16).

Over half of the mothers said that they would have liked to have breastfed for longer (20/37, (54%)). Reasons for stopping breastfeeding included inadequate breastmilk supply, issues with expressing breast milk and their infants having faltering growth. The quotes in Table 4 illustrate the reasons mothers gave for stopping breastfeeding.

Mothers were asked "What would have helped you breastfeed longer?" the answers included not introducing bottles as early, not needing to express, being at home and having more specific support. Quotes from the initial, 7-month and 12-month questionnaires in response to this question are given in Table 4. Some mothers also used this question to explain that they did breastfeed.

Discussion:

We have shown that exclusive breastfeeding amongst the infants with DS at six months is comparable to the general population (4% vs 1%). Apart from exclusive breastfeeding at six weeks when prevalence was similar (21% of infants with DS versus 23% in the general population), breastfeeding (exclusive or combination feeding) amongst the study participants was higher at all time points than levels reported in the general population (15). This was surprising and does not support the hypothesis that hypotonia and oro-motor issues associated with DS significantly alters ability to breastfeed. This is an important and encouraging message for mothers and should inspire midwives and health professionals to support breast feeding. These findings suggest that the frequently heard mantra, that infants with DS probably will not breastfeed successfully, needs to be changed.

Formula was introduced very early at a median of five days with 77% having started by the age of six weeks. Overall, over half of the mothers were still breastfeeding beyond the age of six months (including infants who combination fed with breastmilk and infant formula) which is a very positive message for families. This is higher than the 34% at six months within the general population. Due to the wording of the questionnaire, it was not possible to distinguish between those who directly breastfed or those who gave expressed breastmilk, and this would be useful to include in future questionnaires.

Over half of FADES infants were admitted to SCBU, all being NG tube fed. In around 40%, issues with feeding were responsible for NG placement and for most of these participants, this was also the reason for SCBU admission. Almost 70% of the mothers said that having their baby in SCBU had affected their ability to feed the way they would have liked. This is possibly open to intervention as some admissions might be prevented with more specialised/tailored support on the postnatal wards. Some hospitals will only have one or two infants born a year with DS, possibly leading to automatic SCBU admissions with increased levels of anxiety around potential complications and associated conditions. In terms of oro-motor skill development, it is important that infants have the chance to feed orally early on. This is postulated to be important for the development of oral skills, tolerance of tastes and textures and is also important for social development (17). Most infants in our cohort required NG tube feeds for less than two weeks but a third also required feeds to be stopped altogether at some point and were put onto intravenous fluids.

NG tube feeding was required for some infants due to dehydration, jaundice, polycythaemia and vomiting. Although classified as a ‘medical’ reason, inability to feed may have contributed or caused these issues. Other ‘medical’ reasons included prematurity, ventilation or surgical abdomen. Prevalence of NG tube feeding in the general population and in the typical DS population are poorly reported. A third of those NG fed infants continued to receive exclusively expressed breastmilk. Many of the infants were fed using expressed breastmilk either for NG tube feeds or for top up feeds via alternative feeding methods including bottle.

Lethargy was the most commonly reported problem with feeding after discharge with far fewer citing poor latch than during the initial admission. Importantly 16% of the mothers said that poor weight gain or weight loss was an issue. It is of concern that over a quarter of the mothers reported that they were not given the correct ‘DS insert’ in their Personal Child Health Record (‘Red’ book) (16). Healthy infants with DS gain weight more slowly than other infants and it is important to account for this when assessing feeding and growth. If an infant with DS is plotted on a standard growth chart they will appear to be failing to thrive and a mother who is successfully feeding her baby, may be told that she needs to supplement feeds, start formula feeds if she is breastfeeding or even that her baby needs admission to hospital.

Although the number of participants is relatively high compared to other cohorts of infants with DS, the small number in this paper means that caution needs to be used when drawing conclusions. Those infants born with a child protection plan, fostered, or adopted, and parents who do not speak English did not meet the inclusion criteria. Therefore, we are likely to have excluded some of the most disadvantaged of our population. The higher levels of breastfeeding in the study compared to the general population may in part, be due to selection bias. Mothers who have chosen to take part in the study may already have a specific interest in infant feeding. In the UK, higher breastfeeding frequency is described in mothers over 30 years of age (87%) (15) which may also explain the higher level of initial breastfeeding in FADES. The karyotype for the infants in the cohort was not requested which might be considered a weakness of the study. FADES potentially might include children with mosaic Down syndrome who can be phenotypically milder although this is rare: Only one to three percent of DS children have Mosaicism (18).

Reasons for stopping breastfeeding were similar to the IFS 2010 (15) with inadequate breastmilk supply and faltering growth being common. However, a large proportion mentioned issues surrounding expressing milk. This highlights the need for mothers who are expressing to receive tailored support. Mothers were asked “What would have helped you breastfeed longer” the responses indicated that mothers understandably wanted ‘normality’, they wanted their infants to be well, to not require bottle or expressed milk and to be at home. Although it is not possible to change these factors for many, every effort should be made to listen to maternal wishes and assist where possible. Some mothers used this questionnaire to voice their frustration at alternative feeding methods being introduced ‘too early’ or ‘against their wishes’.

It is a strength of the study that the families recruited were representative of the general population of children with DS, with similar numbers of children having associated conditions including cardiac abnormalities as reported in other studies (19). The eligibility criteria were broad and did not exclude any medical conditions. A further strength is that the study was UK wide reducing selection bias. Those who could not speak English were excluded and this may have had altered feeding results with cultural differences in early feeding (20). Translating all study documentation however was not possible for the multiple languages now represented in UK population.

These results raise some important questions and highlight potential opportunities for interventions in relation to feeding support for mothers of infants with DS. Any advice given to mothers on feeding a baby with DS based on this study should include the message that infants with DS can be exclusively breastfed or receive a combination of breast and formula feeds. However, some may need to include expressed breastmilk and alternative feeding methods. Providing mothers with access to tailored support and advice specifically around expressing should be included, as should information on NG tube feeding.

Conclusion:

This paper provides critical understanding of the early breastfeeding practices and experiences of mothers with infants. It is clear that many infants with DS can breastfeed exclusively for six months as per WHO guidelines. Our study shows that almost two-thirds of babies with DS were being breast fed at 6 months. This may require significant perseverance from the mother and supportive professionals, as establishing breastfeeding can be challenging. Oro-motor difficulties and significant medical needs may underlie some challenges, but overall, mothers who wish to breastfeed should be encouraged and supported to do so as success is possible.

Boxes – What is already known on this topic (bullet points)

- Infants with DS have anatomical and physiological features that may affect their ability to feed but this is phenotypically variable.
- Infants with DS have associated medical conditions including congenital heart disease and gastro-intestinal abnormalities which may impact on early feeding.
- Prevalence of NG Tube feeding in infants with DS has previously been reported as up to 40%.

What this study adds

- Breastfeeding prevalence amongst infants with DS are equivalent to the general population at 6 months.
- Infants with DS can receive exclusive breast-milk feeds for over 6 months.
- Early and extra post-natal support for breast feeding may be beneficial.
- At least half of infants with DS in this UK wide cohort study receive nasogastric feeds.

How this Study might affect research, practice or policy

- This study seeks to promote an increase in tailored feeding support for mother’s of infants with DS.
- Key findings from this study may contribute to positive changes in breastfeeding advice and support for mother’s of infnats with DS.
- The high prevalence of infants receiving naso-gastric tube feeds warrants further research and potentially change in policy within neonatal units.

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Competing interests: No competing interests

Authors Contribution: Georgina M.G. Williams was the chief investigator and PhD student, wrote the protocol, completed the data collection, data analysis and drafts of the manuscript. Sam Leary was the lead statistician on the study and PhD supervisor. She contributed to the protocol and study design, data analysis and draft manuscripts of the paper. Sofia Leadbetter provided the administrative support and coordination for the study, she was involved in participant recruitment and data collection. Stu Toms contributed to the study design, online questionnaires and managed the study database. Georgina Mortimer contributed to the data collection and coordinates sample collection for the FADES study. Tim Scorrer recruited participants for the study and reviewed draft manuscripts of the paper. Kathleen Gillespie (PhD supervisor) contributed to the study protocol, study design and reviewed draft manuscripts of the article. Julian Hamilton Shield (PhD supervisor) contributed to the study protocol, study design and reviewed draft manuscripts of the articles.

Data Sharing: Data sets may only be available by individual request to the Corresponding Author.

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Establishing breast feeding in Infants with Down syndrome: the FADES cohort experience

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Title Page:

Establishing breast feeding in infants with Down syndrome: the FADES cohort experience

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Abstract:

Objective: To describe breast feeding prevalence, and maternal experience in infants with Trisomy 21.

Design: Longitudinal cohort study

Setting: Participants from UK recruited through websites, social media and local collaborators: neonatologists, community paediatricians and research nurses.

Subjects: Infants under the age of 8 months with Down syndrome (DS) recruited to the FADES (Feeding and Autoimmunity in Down Syndrome Evaluation Study) between the 1st September 2014 to 31st August 2017. Seventy participants: median age 20 weeks (Interquartile range (IQR) 13, 29 weeks) at initial questionnaire.

Main outcome measure: Breastfeeding prevalence at 6 weeks and 6 months amongst infants with DS.

Results: The prevalence of exclusive breastfeeding amongst study participants was similar to the general population (13/61 21% vs 23% at 6 weeks, 2/54 4% vs 1% at 6 months). However, the prevalence of breastfeeding (exclusive or combination feeding) amongst the study participants was higher than the general population (39/61 64% vs 55% at 6 weeks, 32/59 54% vs 34% at 6 months).

Conclusion: Although there may be challenges in establishing breastfeeding in infants with DS, our data suggest that exclusive breastfeeding is possible for some, and the prevalence of breastfeeding is comparable to the prevalence in the general population.

Trial Registration: ISRCTN 12415856

Keywords: Down Syndrome, Trisomy 21, Feeding, Breast-feeding,

Background

Down syndrome (DS) is caused by trisomy of chromosome 21. DS is usually diagnosed antenatally or in the first few days of life by recognition of salient features (1). A number of associated conditions including congenital heart disease and gastrointestinal complications can cause additional challenges during the neonatal period.

Current World Health Organisation (WHO) recommendations are that infants should be exclusively breastfed until 6 months (5), this is based on the health benefits for mother and baby. Prolonged exclusive breastfeeding is possibly protective against some autoimmune conditions including type 1 diabetes and coeliac disease for which children with DS are at increased risk (6,7,8). Furthermore, there is evidence that breastfeeding exclusively or combined feeding to a lesser but significant extent, enhances immunity and is protective against otitis media and respiratory tract infections (9) both being more prevalent in children with DS (10).

Infants with DS may have oral, anatomical and physiological abnormalities affecting their ability to feed normally: as with other features of DS there is phenotypic variability. To breastfeed effectively, a tight oral/nipple seal needs to be induced with the tongue making a groove and the lips sealing around the nipple. For a baby with DS, the flattened shape of the tongue and low tone in the oral structures means that establishing breastfeeding may be challenging. (2,3). Lewis et al reported that 40% of DS infants had been naso-gastric (NG) tube fed during the neonatal period illustrating some of the issues with feeding (4).

Many countries have registers which provide data on people with DS. These have facilitated retrospective studies providing statistics on for example: birth and death rates and congenital anomalies. However longitudinal birth cohort studies of infants with DS in the UK are rare (11,12,13,14). The FADES (Feeding and Autoimmunity in Down Syndrome Evaluation Study) was established to investigate early feeding and the development of autoimmunity. Medical and detailed feeding data are collected by mothers from birth and includes both feeding in the hospital settings and at home. A study hypothesis is that infants with DS have difficulties with establishing breast feeding and are therefore introduced to formula feeds at an earlier age. The aim of this paper is to describe breastfeeding prevalence and experiences among infants with DS and their mothers, in the first six months of life. This paper describes findings from the analysis of the feeding data collected between September 2014 and August 2017, to explore this and compare to breastfeeding prevalence in the general population.

Methods:

FADES is an ongoing UK wide study recruiting infants with DS antenatally or in the first eight months of life. Exclusion criteria are infants born with a child protection plan, fostered or adopted, >8 months or parents do not speak English. Participants are recruited either by health professionals including neonatologists, community paediatricians and research nurses or via web recruitment through the Downs Syndrome Association, Downs Syndrome Scotland, and other websites and social media https://www.bristolbrc.nihr.ac.uk/our-research/nutrition-diet-and-lifestyle/childhood/fades-study-2/. A combined feeding and medical questionnaire is completed by families at recruitment (initial questionnaire), at six to eight months of life (7-month questionnaire) and then at 12 months (12-month questionnaire). Feeding questions are based on those from the Infant Feeding Survey (IFS) 2010 (15), medical questions are related to conditions associated with DS, hospital admissions and antibiotic usage. Mothers are able to provide free text answers to some questions and quotes from these have been used to illustrate key points. A full qualitative study and analysis has not been completed as part of this feasibility study. This paper presents data collected in the first three years of recruitment from 1st September 2014 to 31st August 2017 when the feasibility assessment was conducted.

Statistical Analysis: As a feasibility study, analysis of the questionnaires is descriptive as there is not enough power to statistically test for associations. Frequencies were derived and presented as percentages for categorical variables. For continuous data, means and standard deviations (SDs) were presented for data that were approximately normal, and medians and interquartile ranges (IQRs) for non-normal data. Analysis used STATA vs. 15. Comparisons are made with the general population from the results reported by the IFS 2010 (15).

Public involvement: The study design including recruitment and data collection methods were established following discussion with and involvement of the Downs Syndrome Association. Local members (all of whom were parents of a child with DS) advised on the wording and feasibility of the feeding and medical questionnaires.

Ethics approval for FADES was given by the National Research Ethics Service (NRES) Committee South West – Central Bristol 23rd April 2014 14/SW/0030 and it is an NIHR Portfolio study.

Results:

Seventy participants were recruited between the 1st September 2014 and the 31st August 2017. 61 out of the 70 participants (87%) completed the initial feeding and medical questionnaire at a median age of 20 weeks (IQR 13, 29 weeks). Of these, approximately a quarter (n=15) were diagnosed antenatally with DS. Table 1 summarises maternal characteristics and birth details. Over half were born by normal vaginal delivery: median gestation, 38 weeks (IQR 37, 39 weeks), mean birthweight of 3kg (SD 0.5kg). Most infants were born in hospital units, three were home deliveries. Median hospital stay after birth was five days (IQR 3, 9 days).

Background Characteristics		
Maternal age (years) at time of completing initial questionnaire	20 to 24	5/61 (8%)
	25 to 29	6/61 (10%)
	30 to 34	15/61 (25%)
	35 to 39	23/61 (38%)
	40 or over	12/61 (20%)
Mother's marital status	Living together	17/61 (28%)
	Married or in a civil partnership	40/61 (66%)
	Single	3/61 (5%)
	Widowed, divorced, or separated	1/61 (2%)
Mother's ethnic group	Other	2/61 (3%)
	White British	53/61 (87%)
	White Irish	3/61 (5%)
	White Other	3/61 (5%)
Birth History		
First baby		19/61 (31%)
Prenatal diagnosis of DS		15/61 (25%)
Twin Birth		2/61 (3%)
Type of delivery	Normal Vaginal delivery	38/60 (63%)
	C-Section	17/60 (28%)
	Forceps	2/60 (3%)
	Ventouse	3/60 (5%)
Gestation (weeks)	Median 38 (IQR 37, 39)	
Pre-term 32-37 weeks		13/61 (21%)
Birthweight (kg)	Mean 3.0 (0.5 SD)	
Location of birth	At home	3/59 (5%)
	In hospital (consultant led)	29/59 (50%)
	In hospital (midwife led)	25/59 (42%)
	Birth centre (midwife led)	2/59 (3%)
Length of initial hospital stay (hours)	Median 120 (IQR 72, 216)	

Table 1: Maternal characteristics and birth details

Footnote: DS (Down syndrome), IQR (inter quartile range), SD (standard deviation), C-section (Caesarean Section)

Over half (34/61, 56%) were admitted into a special care baby unit (SCBU) with almost a third of these (10/34, 29%) primarily due to poor feeding. Half of the infants for whom data were available, required NG tube feeding as shown in Table 2. All admitted to SCBU, were NG tube fed. Of the 31 infants who were fed via NG tube, 12/31 (39%), primarily required

NG tube feeds in SCBU due to feeding issues, the remainder due to medical co-morbidities (37% with multiple medical indications). NG tube feeds were mostly expressed breastmilk or a mixture of expressed milk and infant formula. NG tube feeds were required in 19/31 (61%) participants for less than two weeks.

SCBU Admission		
Admitted to SCBU		34/61 (56%)
Admitted to SCBU due to problems with feeding		10/34 (29%)
Admitted to SCBU for any other reason*		24/34 (71%)
Hypoxia / respiratory distress / PPHN		17/34 (50%)
Jaundice		7/34 (21%)
Cardiac / cardiac monitoring		4/34 (12%)
Infection		4/34 (12%)
Prematurity		3/34 (9%)
Polycythaemia		2/34 (6%)
Other		7/34 (21%)
Length of SCBU stay (weeks)		Median 2 (IQR 2, 4)
Feeding in SCBU and NG tube Feeds		
SCBU admission affected ability of mother to feed baby as she would have liked		23/34 (68%)
Shown how to express milk in SCBU		29/34 (85%)
Felt supported to express milk in SCBU		27/30 (90%)
Had NG tube feeds		31/31* (100%)
Required NG tube feeds due to problems with feeding		12/31 (39%)
Medical reason for NG tube feeds**	Prematurity	2/19 (11%)
	Dehydration / hydration	2/19 (11%)
	Ventilation	2/19 (11%)
	Respiratory problems	8/19 (42%)
	Jaundice / polycythaemia	4/19 (21%)
	Vomiting or surgical abdomen	4/19 (21%)
Length of time NG tube fed	< 3 days	5/31 (16%)
	> 3 to 7 days	6/31 (19%)
	> 1 to 2 weeks	8/31 (26%)
	> 2 to 4 weeks	6/31 (19%)
	> 1 to 2 months	5/31 (16%)
	> 2months	1/31 (3%)
Type of NG tube feeds given	Only expressed breast milk	10/31 (32%)
	Only infant formula	2/31 (7%)
	Expressed breast milk and infant formula	19/31 (61%)
Feeds stopped and IV fluids given		11/34 (32%)
Length of time on IV fluids	< 3 days	2/9 (22%)
	> 3 to 7 days	4/9 (44%)
	> 7 days to 1 month	3/9 (33%)

Table 2: Feeding in SCBU (special care baby unit) and NG (naso-gastric) tube feeds

Footnote: IV fluids (Intra- venous fluids), PPHN (persistent pulmonary hypertension of the newborn),
*Due to an issue with branching of the questions at least 31 infants were NG tube fed but there may have been more. Where they were branched away, people have been counted as missing, so the denominator is 31.
**Coded from open response

Of the mothers receiving an antenatal diagnosis for their baby, 13/15 (87%) were told about problems relating to feeding but only three (3/15, (20%)) received any specific antenatal advice about breastfeeding a baby with DS. Most mothers initially breastfed their baby, with 47/60 (78%) having skin to skin contact within 24 hours of birth (Table 3). Feeding problems that were experienced in the hospital or birthing centre by mothers, included those commonly associated with infants with DS such as poor latch and lethargy. Although hypotonia is one of the explanations frequently given as a cause for feeding difficulties, only one parent described this feature. Mothers provided responses to an open question regarding feeding their baby in the hospital, birth centre or unit as illustrated in the quotes in Table 4.

First Feeds		
Ever breastfed or received expressed breast milk		55/61 (90%)
Had skin to skin contact within 24hrs of birth		47/60 (78%)
Maternal health problems after birth that affected feeding		4/61 (7%)
Received help with breastfeeding within first few days		40/60 (67%)
How soon after birth was baby put to the breast	within a few minutes	14/55 (26%)
	<30 min	17/55 (31%)
	30 min to 1 hr	9/55 (16%)
	>1 hr to 8 hrs	3/55 (6%)
	>8 hrs to 24 hrs	3/55 (6%)
	> 24 hrs later	9/55 (16%)
Experienced problems when feeding their baby in the hospital, birth centre or unit		45/58* (78%)
Common problems with feeding**	Poor latch	20/45 (44%)
	Medical issue	14/45 (31%)
	Jaundice	14/45 (31%)
	Tired / lethargic	13/45 (29%)
	Maternal reason	4/45 (9%)
	Tongue size/ position	3/45 (7%)
	Low tone	1/45 (2%)
Reported that they received enough help with feeding in hospital / birth centre		48/58 (83%)
General Feeding and feeding after discharge from hospital / birth centre		
Problems with feeding baby after discharge from hospital / birth centre		30/56 (54%)
Problems with feeding after discharge**		
	Lethargy	13/61 (21%)
	Poor weight gain / weight loss	10/61 (16%)
	Low tone	1/61 (2%)
	Latch	5/61 (8%)
	Medical	3/61 (5%)
	Jaundice	3/61 (5%)
	Reflux	3/61 (5%)
Received help or information with feeding problems after discharge		27/32*** (84%)

Table 3: First feeds and feeding after discharge

Footnote:* Three infants were home births ** These problems were coded from open responses
***This denominator comes from the 30 participants who experienced problems with feeding after discharge from hospital and two who experienced problems with feeding after their home birth.

Question from initial questionnaire	**'Were there any problems feeding your baby while you were in the hospital, birth centre or unit? What problems were there?'**
Quotes	*"X would not take anything from the breast and was very sleepy so had an NG tube put in."* *"A feeding tube was inserted straight away, which prevented me from breast feeding. It also prevented her from becoming hungry enough to feed from me"* *"baby continually pushing tongue out and could not latch on. Decided to try the bottle which she took immediately so did not try breast again and was not questioned by staff"*
Question from Initial, 7 month and 12 month questionnaire	**'Have you stopped breastfeeding (no longer give your baby any expressed milk or put your baby to your breast)? What were your reasons for stopping?'**
Quotes	*"Significant weight loss in early days, poor latch, inadequate milk being taken by baby, readmission to hospital for tube feeding, introduction of bottle feeding in hospital, milk supply subsequently drying up due to baby being put on bottle and use of pumps further made milk supply deteriorate."* *"Baby fell asleep too much at the breast to feed properly. It was too time consuming and stressful to keep expressing."*
Question from initial, 7-month and 12-month questionnaires	**"What would have helped you breastfeed longer?"**
Quotes	*"Knowing as I do now that it's common to have feeding problems with Down syndrome. More specific breastfeeding support." (from initial questionnaire)* *"I feel I was forced to give Child's name a bottle when she was only a day old as the midwife was unwilling to entertain my concerns about the bottle meaning that she would never take the breast. I had wanted to give the milk by syringe or cup to give her a chance to keep trying the breast, but I was shot down and ridiculed." (from 7-month questionnaire)* *"I just became too sick, unwell but at the same time I fed longer than I thought I would. Thanks to the support I received." (from 12-month questionnaire)* *"She lost 6% of her birth weight by day 9 and the NICU home midwife suggested we move onto top up. I think that was the pinch point. If I had said no, let's try harder to feed from the breast it might have established itself. But*

	she had just been discharged from hospital and I was so reluctant to go back. You really have the threat of readmission hanging over you… I would have loved to feed her myself. It is my biggest sadness but there were too many other variables at play. I am pleased I was able to exclusively breast feed her though for well over 4 months." (from 12-month questionnaire)

Table 4: Quotes from free text boxes in initial, 7 month and 12 month questionnaire

Of the 61 mother/baby dyads, 39 (64%) continued some breastfeeding for over six weeks (Table 5) (including infants who received mixed infant formula and breastmilk feeds). Over the age of six months, this decreased to 32 (32/59 (54%)) still breastfeeding in part. These percentages are higher than in the general population, levels reported in the Infant Feeding Survey (IFS) 2010 (55% and 34% respectively) (15). The prevalence of exclusive breastfeeding in the study population at six weeks was 13/61 (21%) compared to 23% in the general population in the IFS 2010 (15). By six months of age, two (2/54 (4%)) participants were exclusively breast fed. This compares to 1% of general population. Using data from the initial and 7-month questionnaires, the median age at which some formula milk was introduced in the whole cohort was five days (IQR 1, 21 days). Formula feeds were introduced by 52% of mothers within a week in the IFS 2010 and 75% by 6 weeks.

Types of feeds / Stopping breastfeeding			
Age stopped breastfeeding*			
6 weeks or less	11/27** (41%)		
> 6 weeks to 4 months	7/27 (26%)		
> 4 months to 6 months	3/27 (11%)		
> 6 months	6/27 (22%)		
Age started formula feeds			
6 weeks or less	44/57*** (77%)		
> 6 weeks to 4 months	3/57 (5%)		
> 4 months to 6 months	5/57 (9%)		
> 6 months	5/57 (9%)		
Age when given a non – milk drink**** (weeks)	Median 26 (IQR 20, 28)		
Age at which first given cow's milk (weeks)	Median 44 (IQR 28, 48)		
Stopping breastfeeding and problems with feeding	Initial Questionnaire	7 month Questionnaire	12 month Questionnaire
Maternal opinion on how long they breastfed			
Breastfed for as long as they intended	14/37(38%)	4/23 (17%)	4/20 (20%)
Breastfed for longer than they intended	3/37 (8%)	3/23 (13%)	3/20 (15%)
Would have liked to breastfeed longer.	20/37 (54%)	16/23 (70%)	13/20 (65%)
Reasons for stopping breastfeeding			
Inadequate breastmilk supply	6/20 (30%)	7/54 (13%)	2/40 (5%)
Problems expressing milk	5/20 (25%)	3/54 (6%)	4/40 (10%)
Excessive time expressing milk	5/20 (25%)	1/54 (2%)	2/40 (5%)
Baby losing weight	4/20 (20%)	2/54 (4%)	2/40 (5%)
Maternal medical problem	3/20 (15%)	2/54 (4%)	1/40 (3%)
Lethargy	1/20 (5%)	1/54 (2%)	
Weaning by choice	n/a	4/54 (7%)	3/40 (8%)
Other		3/54 (6%)	4/40 (10%)

Table 5: Stopping Breastfeeding

*Footnote: *including using expressed breastmilk and mixed feeding and/or were introduced to other types of milk feeds or drinks. **this denominator is the number of women who had stopped breastfeeding by the data cut off date for data analysis. Some infants would still have been receiving breastmilk at the cut-off date for data analysis. Some would also have been still mixed feeding both breastmilk and formula ****Non-milk drinks included any drink other than milk including water (which would be fine) and juices which would not be recommended.*

Just over half of the participants had problems associated with feeding after discharge from hospital (Table 3). The most common problems were lethargy or faltering growth. Three mothers mentioned their infants being readmitted to hospital with poor feeding. Less than three-quarters, 34/47 (72%) had the correct 'DS insert' in their Red book (the personal child health record that is given to every baby). The 'DS insert' contains the appropriate growth charts reflecting a tendency to 'normal', slower growth trajectory in this condition compared to non-trisomy infants (16).

Over half of the mothers said that they would have liked to have breastfed for longer (20/37, (54%)). Reasons for stopping breastfeeding included inadequate breastmilk supply, issues with expressing breast milk and their infants having faltering growth. The quotes in Table 4 illustrate the reasons mothers gave for stopping breastfeeding.

Mothers were asked "What would have helped you breastfeed longer?" the answers included not introducing bottles as early, not needing to express, being at home and having more specific support. Quotes from the initial, 7-month and 12-month questionnaires in response to this question are given in Table 4. Some mothers also used this question to explain that they did breastfeed.

Discussion:

In our cohort exclusive breastfeeding amongst the infants with DS at six months is comparable to the general population (4% vs 1%). Apart from exclusive breastfeeding at six weeks when prevalence was similar (21% of infants with DS versus 23% in the general population), breastfeeding (exclusive or combination feeding) amongst the study participants was higher at all time points than levels reported in the general population (15). This was surprising and does not support the hypothesis that hypotonia and oro-motor issues associated with DS significantly alters ability to breastfeed. This is an important and encouraging message for mothers and should inspire midwives and health professionals to support breast feeding. These findings suggest that the frequently heard mantra, that infants with DS probably will not breastfeed successfully, needs to be changed.

Formula was introduced very early at a median of five days with 77% having started by the age of six weeks. Overall, over half of the mothers were still breastfeeding beyond the age of six months (including infants who combination fed with breastmilk and infant formula) which is a very positive message for families. This is higher than the 34% at six months within the general population. Due to the wording of the questionnaire, it was not possible to distinguish between those who directly breastfed or those who gave expressed breastmilk, and this would be useful to include in future questionnaires.

Over half of FADES infants were admitted to SCBU, all being NG tube fed. In around 40%, issues with feeding were responsible for NG placement and for most of these participants, this was also the reason for SCBU admission. Almost 70% of the mothers said that having their baby in SCBU had affected their ability to feed the way they would have liked. This is possibly open to intervention as some admissions might be prevented with more specialised/tailored support on the postnatal wards. Some hospitals will only have one or two infants born a year with DS, possibly leading to automatic SCBU admissions with increased levels of anxiety around potential complications and associated conditions. In terms of oro-motor skill development, it is important that infants have the chance to feed orally early on. This is postulated to be important for the development of oral skills, tolerance of tastes and textures and is also important for social development (17). Most infants in our cohort required NG tube feeds for less than two weeks but a third also required feeds to be stopped altogether at some point and were put onto intravenous fluids.

NG tube feeding was required for some infants due to dehydration, jaundice, polycythaemia and vomiting. Although classified as a 'medical' reason, inability to feed may have contributed or caused these issues. Other 'medical' reasons included prematurity, ventilation or surgical abdomen. Prevalence of NG tube feeding in the general population and in the typical DS population are poorly reported. A third of those NG fed infants continued to receive exclusively expressed breastmilk. Many of the infants were fed using expressed breastmilk either for NG tube feeds or for top up feeds via alternative feeding methods including bottle.

Lethargy was the most commonly reported problem with feeding after discharge with far fewer citing poor latch than during the initial admission. Importantly 16% of the mothers said that poor weight gain or weight loss was an issue. It is of concern that over a quarter of the mothers reported that they were not given the correct 'DS insert' in their Personal Child Health Record ('Red' book) (16). Healthy infants with DS gain weight more slowly than other infants and it is important to account for this when assessing feeding and growth. If an infant with DS is plotted on a standard growth chart they will appear to be failing to thrive and a mother who is successfully feeding her baby, may be told that she needs to supplement feeds, start formula feeds if she is breastfeeding or even that her baby needs admission to hospital.

Although the number of participants is relatively high compared to other cohorts of infants with DS, the small number in this paper means that caution needs to be used when drawing conclusions. Those infants born with a child protection plan, fostered, or adopted, and parents who do not speak English did not meet the inclusion criteria. Therefore, we are likely to have excluded some of the most disadvantaged of our population. The higher levels of breastfeeding in the study compared to the general population may in part, be due to selection bias. Mothers who have chosen to take part in the study may already have a specific interest in infant feeding. In the UK, higher breastfeeding frequency is described in mothers over 30 years of age (87%) (15) which may also explain the higher level of initial breastfeeding in FADES. The karyotype for the infants in the cohort was not requested which might be considered a weakness of the study. FADES potentially might include children with mosaic Down syndrome who can be phenotypically milder although this is rare: Only one to three percent of DS children have Mosaicism (18).

Reasons for stopping breastfeeding were similar to the IFS 2010 (15) with inadequate breastmilk supply and faltering growth being common. However, a large proportion mentioned issues surrounding expressing milk. This highlights the need for mothers who are expressing to receive tailored support. Mothers were asked “What would have helped you breastfeed longer” the responses indicated that mothers understandably wanted ‘normality’, they wanted their infants to be well, to not require bottle or expressed milk and to be at home. Although it is not possible to change these factors for many, every effort should be made to listen to maternal wishes and assist where possible. Some mothers used this questionnaire to voice their frustration at alternative feeding methods being introduced ‘too early’ or ‘against their wishes’.

It is a strength of the study that the families recruited were representative of the general population of children with DS, with similar numbers of children having associated conditions including cardiac abnormalities as reported in other studies (19). The eligibility criteria were broad and did not exclude any medical conditions. A further strength is that the study was UK wide reducing selection bias. Those who could not speak English were excluded and this may have had altered feeding results with cultural differences in early feeding (20). Translating all study documentation however was not possible for the multiple languages now represented in UK population.

These results raise some important questions and highlight potential opportunities for interventions in relation to feeding support for mothers of infants with DS. Any advice given to mothers on feeding a baby with DS based on this study should include the message that infants with DS can be exclusively breastfed or receive a combination of breast and formula feeds. However, some may need to include expressed breastmilk and alternative feeding methods. Providing mothers with access to tailored support and advice specifically around expressing should be included, as should information on NG tube feeding.

Conclusion:

It is clear that many infants with DS in our cohort can breastfeed exclusively for six months as per WHO guidelines. Our study shows that almost two-thirds of babies with DS were being breast fed at 6 months. This may require significant perseverance from the mother and supportive professionals, as establishing breastfeeding can be challenging. Oro-motor difficulties and significant medical needs may underlie some challenges, but overall, mothers who wish to breastfeed should be encouraged and supported to do so as success is possible.

Boxes – What is already known on this topic (bullet points)

- Infants with DS have anatomical and physiological features that may affect their ability to feed but this is phenotypically variable.
- Infants with DS have associated medical conditions including congenital heart disease and gastro-intestinal abnormalities which may impact on early feeding.
- Prevalence of NG Tube feeding in infants with DS has previously been reported as up to 40%.

What this study adds

- Breastfeeding prevalence amongst infants with DS are equivalent to the general population at 6 months.
- Infants with DS can receive exclusive breast-milk feeds for over 6 months.
- Early and extra post-natal support for breast feeding may be beneficial.
- At least half of infants with DS in this UK wide cohort study receive nasogastric feeds.

How this Study might affect research, practice or policy

- This study seeks to promote an increase in tailored feeding support for mother's of infants with DS.
- Key findings from this study may contribute to positive changes in breastfeeding advice and support for mother's of infnats with DS.
- The high prevalence of infants receiving naso-gastric tube feeds warrants further research and potentially change in policy within neonatal units.

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Data Sharing: Data sets may only be available by individual request to the Corresponding Author.

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