

Prevalence and Patterns of Enteral Feeding in Infants with Down Syndrome

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Background

- Feeding difficulties and dysphagia (difficulty swallowing) occur frequently in infants with Down syndrome (DS). Reported feeding challenges include **differences in state regulation, fatigue, difficulty sucking, weakness of the oral structures, choking/coughing, difficulty breathing, poor weight gain**, and some infants require enteral tube placement early in life.
- Preterm infants** with DS may be particularly vulnerable due to their underdeveloped anatomy and early feeding experiences.
- Medical** and **developmental co-occurring conditions** can exacerbate the health consequences caused by feeding difficulties.
- Infants with enteral tube feeding dependence are at risk of developing impaired oral feeding skills.

Methods

- We retrospectively reviewed the presence of enteral tube feeding in 96 infants with DS ages **birth to one year of age** receiving care at a large specialty pediatric DS clinic between 2019 and 2022.
- Patients were identified from a clinic database and medical charts were reviewed for clinical details including feeding status, use of enteral tubes, gestational age at birth, hospitalizations, medical co-occurring conditions, and nutrition status and management.
- Feeding and swallowing difficulties were coded based on information obtained from the **feeding evaluation completed at time of the DS clinic visit**. Presence of feeding therapy was also obtained from this evaluation report.



Results

Demographics

- 53.1%** (n=52/96) infants with DS required enteral feeding support during their **birth hospital stay** (TABLE 1).
- Overall, **60.2%** (n=59/96) required this support during the **first year of life**.

Impact of Co-Occurring Conditions

- Of the 52 infants with DS that required enteral feeding support during their birth hospital stay:
 - Enteral feeding continued in **21.2%** (n=11) **beyond their discharge**.
- Risk ratios** were calculated for co-occurring conditions. (TABLE 2)

TABLE 1. Demographics by patient group

	Total n (%)	Enteral Feeding During Birth Hospitalization n (%)	Enteral Feeding During First Year n (%)
Total	96 (100.0)	52 (100.0)	59 (100.0)
Sex			
Female	52 (54.2)	29 (55.8)	34 (57.6)
Male	44 (45.8)	23 (44.2)	25 (42.4)
Race/Ethnicity			
White	48 (50.0)	25 (48.1)	29 (49.2)
Hispanic/Latino	32 (33.3)	15 (28.8)	17 (28.8)
Black or African American	5 (5.2)	2 (3.8)	3 (5.1)
More than one race	2 (2.1)	2 (3.8)	2 (3.4)
Other	4 (4.2)	3 (5.8)	3 (5.1)
Unknown	5 (5.2)	5 (9.6)	5 (8.5)
Age at first SC appointment (mean in years, SD)	0.38 (0.27)	0.40 (0.27)	0.39 (0.26)

TABLE 2. Relative risk of co-occurring conditions on enteral feeding during birth hospital stay

	Total Comorbidity n	During Birth Hospitalization (n = 52)				Continued After Birth Hospitalization (n = 11)			
		No Enteral Feeding n (%)	Enteral Feeding n (%)	p-value	Relative Risk	No Enteral Feeding n (%)	Enteral Feeding n (%)	p-value	Relative Risk
Dysphagia	19	2 (4.5)	17 (32.7)	p ≤ 0.001	7.3	14 (16.5)	5 (45.5)	p = 0.038	2.8
Preterm (36 weeks or earlier)	28	6 (13.6)	22 (42.3)	p = 0.002	3.1	24 (28.2)	4 (36.4)	p = 0.725	-
PPHN/Pulmonary hypertension	27	7 (15.9)	20 (38.5)	p = 0.014	2.4	21 (24.7)	6 (54.5)	p = 0.069	-
Congenital heart surgery	19	7 (15.9)	12 (23.1)	p = 0.380	-	14 (16.5)	5 (45.5)	p = 0.038	2.6
GI structural abnormalities	12	5 (14.7)	7 (14.9)	p = 0.981	-	8 (11.3)	4 (40.0)	p = 0.037	3.5
General neonatal complications									
Required oxygen	61	21 (47.7)	40 (76.9)	p = 0.003	1.6	56 (65.9)	5 (45.5)	p = 0.201	-
CPAP	13	3 (6.8)	10 (19.2)	p = 0.132	-	13 (15.3)	0 (0.0)	p = 0.351	-
Respiratory distress syndrome	11	3 (6.8)	8 (15.4)	p = 0.218	-	10 (11.8)	1 (9.1)	p = 1.000	-

Feeding Status, Therapeutic Intervention, and Nutritional Management at First Clinic Appointment (TABLE 3)

TABLE 3. Report of feeding and swallowing difficulties in clinical feeding evaluation

	n	Feeding Difficulties	Confirmed Dysphagia	Concern for Dysphagia	Feeding Therapy	Medical Provider or Dietitian Management of Nutrition
Infants WITH Enteral Tube Feeding	16	15 (93.8)	7 (43.8)	2 (12.5)	6 (42.9)	3 (18.8)
Infants WITHOUT Enteral Tube Feeding	76	55 (72.4)	6 (7.9)	25 (32.9)	21 (31.3)	15 (19.7)
TOTAL	92	70 (76.1)	13 (14.1)	27 (29.3)	27 (33.3)	18 (19.6)

Data available on 92/96 patients

Objectives

- Identify the groups of infants with DS that are most at risk for enteral tube feeding in their first year of life.
- Examine the co-occurring conditions of infants with enteral feeding tubes to determine any correlations.
- Compare presence of feeding difficulties, dysphagia, feeding intervention, and nutritional management in infants with and without enteral tube feeding at time of first visit in a DS specialty clinic.

Conclusions/Implications

- Several co-occurring conditions increase risk for enteral tube feeding dependence.
 - During the **birth hospital stay**: Dysphagia, prematurity, PPHN/pulmonary hypertension, GI structural abnormalities, and oxygen support.
 - Continued **beyond** the birth hospital stay: Dysphagia, congenital heart surgery, and GI structural abnormalities.
- Future research is needed to establish care models to support infants with enteral tube feeds following hospital discharge.
- Despite the high incidence of feeding difficulties, only one third of infants received feeding therapy and one fifth receive appropriate nutrition counseling. More timely feeding and nutrition support is necessary to promote feeding success in infants with DS.
- Determining the best approach to feeding and nutrition coordination in infancy has the potential to **reduce variability regarding enteral feeding initiation** and **potential associated complications**.

Disclosures

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