

## Sucking Patterns in Infants with Down Syndrome admitted to a Level 4 Neonatal Intensive Care Unit

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**Objective:** Infants with Down syndrome present multiple challenges that can affect growth and development, among them feeding, difficulties that arise in the early days after birth. We aimed to describe the sucking patterns of infants with Down syndrome in the neonatal intensive care unit (NICU).

**Methods:** We reviewed the medical records of infants with Down syndrome admitted (2012–2022) to the University Pediatric Hospital NICU in San Juan, Puerto Rico, who were evaluated with a clinical swallow examination and the Neonatal Oral-Motor Assessment Scale (NOMAS).

**Results:** The study included 29 infants. The median gestational age was 38 weeks, and the median birth weight was 2650 grams. Generalized low muscle tone was identified in 81% of the infants. Sucking patterns were classified as disorganized (41%), dysfunctional (52%), and mature (7%). Only 8% of term infants had mature sucking. The clinical signs of swallow dysfunction included reduced oxygen saturation (20%), mottling (50%), interference with the gag reflex (31%), stridor (40%), and wet or gurgly breathing (75%).

**Conclusion:** Mature sucking skills are expected in term infants. However, our sample of term infants with Down syndrome had a high prevalence of dysfunctional sucking. Neonates with congenital anomalies associated with hypotonia require a formal assessment with a clinical tool to determine their readiness for oral feeding and may require a complete evaluation of feeding and swallowing for the diagnosis and monitoring of swallowing dysfunction. These assessments will form the basis for the design of evidence-based interventions and may yield valuable information regarding neurodevelopmental outcomes.

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*Key words: Sucking, Down syndrome, Dysphagia, Oral feeding assessment*

The prevalence of Down syndrome in Puerto Rico has shown an upward trend over the past 2 decades, increasing from 9.0 per 10,000 live births in 2001 to 16.8 per 10,000 in 2018, with a subsequent adjustment to 12.6 per 10,000 in 2020 (1). In developed countries, the survival rate of children with Down syndrome surpasses 90% (2). Infants with this condition frequently face multiple challenges that may impact their growth and development, including feeding difficulties that manifest shortly after birth. Common issues include oral-motor difficulties, feeding problems, and pharyngeal dysphagia (3). The aim of this study was to delineate the sucking patterns of infants with Down syndrome who were admitted to the neonatal intensive care unit.

### Methods

We reviewed the medical records of infants with Down syndrome admitted to the University Pediatric Hospital Neonatal Intensive Care Unit in San Juan, Puerto Rico, from 2012 to 2022, who underwent a clinical swallow examination and the Neonatal Oral-Motor Assessment Scale (NOMAS). NOMAS is a reliable tool to assess infants' non-nutritive and nutritive sucking patterns. This 28-item observational checklist evaluates jaw and tongue movements during sucking. It describes these movements based on rate, rhythmicity, the uniformity of jaw excursion, timing, and the configuration of tongue movements. The NOMAS describes the sucking patterns in pre-term and term infants as mature, disorganized, or dysfunctional (4,5). A NOMAS-certified speech

pathologist evaluated all the infants. The University of Puerto Rico Medical Sciences Campus Institutional Review Board approved the study. Descriptive statistical analysis was performed using Intellectus Statistics.

### Results

The study included 29 infants; Table 1 shows their demographic characteristics. Most of the infants (76%) were born at term, and 40% of them had congenital heart disease. Table 2 shows the findings of the clinical bedside swallowing examination, which evaluates the safety and efficiency of oral intake (5). Most of the infants presented generalized low muscle tone (81%) with an open mouth (75%). The most common clinical signs of swallow dysfunction included wet or gurgly breathing (75%), interference with gag reflex (65%), mottling (50%), and stridor (40%). The NOMAS assessment tool was performed at a median of 40 weeks postmenstrual age (33 to 49 weeks), with 90% of infants already

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**Table 1.** Demographic characteristics of infants with Down Syndrome (n = 29)

Characteristic	Median (min-max) or percentage
Gestational age	38 weeks (28–40)
Birth weight	2650 grams (1055–4965)
Sex	
Female	58%
Male	42%
Delivery	
Cesarean	57%
Vaginal	43%
5-minute Apgar score	8 (7–9)

**Table 2.** Clinical bedside swallowing examination (n = 29)

Characteristic	Percentage
<i>Behavioral state</i>	
Quiet alert	61%
Drowsy	27%
Active	8%
Light sleep	4%
<i>Tone</i>	
Generalized low muscle tone	81%
<i>Cheeks</i>	
Low tone	65%
<i>Mouth</i>	
Open	75%
Tongue protrusion	35%
Mild secretions	35%
<i>Clinical signs of swallow dysfunction</i>	
Wet or gurgly breathing	75%
Gagging	65%
Mottling	50%
Stridor	40%
Impaired gag reflex	31%
Coughing	31%
Decreased oxygen saturation	20%

## Discussion

Altered craniofacial structures and functionality in infants with Down syndrome increase difficulties in oral motor performance, feeding, and swallowing (6). Infants with Down syndrome usually have hypotonic, flaccid tongues, poor tongue control, and an open mouth posture, which can interfere with effective oral motor skills and cause feeding difficulties (7,8). Observations in our study group reflected generalized low muscle tone, low cheek muscle tone, an

open mouth, a flaccid, protruding tongue, and mild oral secretions, all of which negatively affected feeding and swallowing. In the clinical swallow exams, the NOMAS categorizes tongue and jaw movements as normal, disorganized, or dysfunctional. Disorganized sucking is defined as a “lack of rhythm in sucking activity,” while dysfunctional sucking involves “interrupted feeding due to abnormal tongue and jaw movements” (9). Infants with Down syndrome often show disorganized and dysfunctional sucking (10); the latter is also common in premature infants, though less so in term infants. Our study found that term infants with Down syndrome frequently had dysfunctional sucking with symptoms such as flaccid tongue, excessive tongue protrusion, and wide jaw movements, all affecting feeding and swallowing (11). Symptoms in newborns included delayed suckling, difficulties in breast and bottle-feeding, an open mouth with drooling when at rest, and silent aspiration (12). A study of 14 infants with Down syndrome (aged 1–12 months) revealed deficient smooth tongue movement, possibly due to hypotonicity in oral and facial muscles (13).

Bottle-fed infants with Down syndrome have weaker, shorter sucking bursts than controls. A study by Coentro et al. (2020) found that these infants breastfed for an average of 2 months, compared to an average of 6 months in healthy infants, with poor sucking cited as a reason for early weaning (10). The authors attributed feeding issues to anatomical and reflex changes, as well as perioral hypotonia, which affects attachment and milk transfer (10). The American Academy of Pediatrics advocates breastfeeding for infants with Down syndrome but notes that early support may be needed for successful nursing. Some infants may also require being awakened for feeding to ensure adequate calorie intake (14). In our group, while most infants were in a quiet, alert state during swallowing exams, one-third were drowsy or lightly asleep, which may have impacted safe and efficient oral intake.

Dysphagia involves difficulty with the phases of swallowing, oral preparatory, oral transit, pharyngeal, and esophageal (15,16). Oral and pharyngeal dysphagia are common and should be evaluated in children with Down syndrome (17,18). Clinical signs of swallow dysfunction include decreased oxygen saturation, gag-reflex issues, stridor, and wet or gurgly breathing, as seen in oropharyngeal dysphagia. Coentro et al. reported that over 50% of infants with Down syndrome in their study showed pharyngeal or oral dysphagia if there was feeding difficulty or suspected aspiration (10). A retrospective review of infants with Down syndrome who underwent video-fluoroscopic swallow studies showed a 90% prevalence of oral and 72% prevalence of pharyngeal dysphagia. Abnormal sucking skills were found in 64% of the study patients, and bolus formation/control was abnormal in 62% (19). These infants were at risk for silent aspiration and recurrent pneumonia (10). A review of 73 children with Down syndrome found that 13.7% required G-tube placement in their first year (20). The American Academy of Pediatrics advises referring infants with hypotonia, failure to thrive, feeding difficulties, or respiratory symptoms for a skilled feeding assessment (14). Feeding plans should ensure infant safety, support developmental feeding abilities, and promote growth (3,7).

Neonates presenting with congenital anomalies associated with hypotonia require a formal assessment using a clinical evaluation tool to ascertain their readiness for oral feedings.

Our cohort, comprising infants with Trisomy 21, exhibited sucking patterns that significantly affected the processes of feeding and deglutition. While NOMAS serves as an effective tool to characterize infantile sucking patterns, a comprehensive evaluation of feeding and swallowing is imperative—potentially supplemented by procedures such as the Modified Barium Swallow Test or the Flexible Endoscopic Evaluation of Swallowing study—for the accurate diagnosis and monitoring of swallowing dysfunction. Such dysfunctions can adversely influence the caloric intake required for both optimal growth and the attainment of developmental milestones in infants. Monitoring these elements of progress will underpin evidence-based interventions and may yield critical insights into neurodevelopmental outcomes.

## Resumen

**Objetivo:** Los infantes nacidos con síndrome de Down presentan múltiples retos que pueden afectar su crecimiento y desarrollo, entre ellos, dificultades para alimentarse después del nacimiento. Nuestro objetivo fue describir los patrones de chupado en infantes con síndrome de Down en la unidad de cuidado intensivo neonatal (UCIN). **Métodos:** Revisamos los expedientes clínicos de infantes ingresados en la UCIN del Hospital Pediátrico Universitario de San Juan, Puerto Rico, de 2012 a 2022 evaluados con examen de tragado y la Escala de Evaluación Oral-Motora Neonatal (NOMAS). **Resultados:** El estudio incluyó 29 sujetos. La mediana de edad gestacional fue de 38 semanas y el peso al nacer de 2650 gramos. Se identificó un bajo tono muscular generalizado en 81%. Los patrones de chupado fueron 41% desorganizado, 52% disfuncional y 7% maduro. Solo 8% de los infantes a término tuvieron chupado maduro. Los signos clínicos de disfunción del tragado incluyeron: disminución de la oxigenación (20%), moteado (50%), interferencia del reflejo nauseoso (31%), estridor (40%) y respiración húmeda (75%). **Conclusión:** Se esperan habilidades de chupado maduras en recién nacidos a término. Sin embargo, nuestra muestra de infantes a término con síndrome de Down presentó una alta prevalencia de chupado disfuncional. Los neonatos con anomalías congénitas asociadas con hipotonía requieren evaluación formal con una herramienta de evaluación clínica para determinar su preparación para alimentarse oralmente y pueden requerir una evaluación de alimentación y deglución para diagnóstico y seguimiento de la disfunción de la deglución. Estas evaluaciones formarán la base para el diseño de intervenciones basadas en evidencia y pueden proporcionar información valiosa sobre el neurodesarrollo.

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