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## Feeding Performance and Outcomes in Infants With Robin Sequence Undergoing Mandibular Distraction Osteogenesis

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### Abstract

**Objective:** To describe perioperative feeding performance in infants with Robin sequence (RS) who underwent mandibular distraction osteogenesis (MDO).

**Design:** A retrospective study of infants that underwent MDO from May 2010 to December 2019.

**Setting:** Tertiary pediatric hospital.

**Patients:** A total of 40 patients underwent MDO and 20 met inclusion criteria. Of the included infants, 6 had an associated syndrome and 80% were male.

**Main Outcome Measures:** Time to full oral feeds, rate of G-tube placement, and change in weight percentile following MDO.

**Results:** Average oral intake prior to MDO was 22.1% of individual goal feeds. Among the 15 (75%) children that did not require G-tube placement, mean time to full oral feeds after MDO was 11 days  $\pm$  5.7 days, with 80% of infants reaching full oral feeds within 2 weeks after extubation. The proportion of G-tube placement in patients with a syndrome was higher than in isolated RS ( $-0.6$ ; 95% CI:  $-1.0$ ,  $-0.2$ ). Mean percentages of weight-for-age percentile decreased during the first 3 months after the procedure. This was followed by a mean upturn in weight starting after

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the third month after MDO with a recovery to preoperative mean weight-for-age percentiles by 6 months after surgery.

**Conclusions:** This study suggests that infants with RS may achieve full oral feeds despite poor feeding performance before MDO. Infants with syndromic RS are more likely to require G-tube. These findings may be used to inform G-tube discussion and offer a timeline to work toward goal oral feeds for infants with RS after MDO.

### Keywords

micrognathia; Pierre Robin sequence; mandibular distraction osteogenesis; feeding

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### Introduction

Robin sequence (RS) is a congenital craniofacial anomaly defined as micrognathia resulting in glossoptosis and airway obstruction.<sup>1,2</sup> The prevalence of RS is estimated to be 1 in 5000 births in the United States.<sup>3</sup> Phenotypic cases of RS can be either isolated or can be seen in conjunction with a syndrome and can lead to feeding complications, airway difficulties, and failure to thrive.<sup>4,5</sup> Syndromic features are present in approximately 60% of patients with RS and Stickler syndrome is the most commonly reported syndrome seen with RS.<sup>6</sup> Approximately 68% of infants with RS are successfully treated with nonsurgical interventions such as prone positioning, nasopharyngeal airway, orthodontic apparatus, or continuous positive airway pressure for upper airway obstruction.<sup>7</sup> Severe or refractory airway obstruction may require more invasive interventions, such as prolonged intubation, tracheostomy, or other surgical techniques such as tongue-lip adhesion and mandibular distraction osteogenesis (MDO).<sup>8</sup> MDO has been well established for treating airway obstruction secondary to micrognathia in the neonatal population. Many early studies focused on tracheostomy avoidance as the main outcome for MDO, with overall success rates reported at over 95%.<sup>9</sup>

However, fewer studies focus on feeding performance surrounding the perioperative period in children with RS. Feeding problems in infants with RS stem from glossoptosis contributing to airway obstruction, insufficient latching, and coordination of swallowing, as well as gastroesophageal reflux disease (GERD).<sup>10-13</sup> Feeding is made even more challenging with the presence of a cleft palate in most infants with RS that hinders intraoral suction and is associated with excessive air ingestion.<sup>3</sup> This sequelae of issues may result in the requirement of nasogastric tube (NG) or gastrostomy tube (G-tube) placement to meet full enteral nutrition goals.<sup>5,8,14-16</sup> Generally, the more severe the respiratory issues, the more difficulty the child with RS has with oral feeding.<sup>14</sup>

Many studies suggest that infants managed with conservative measures continue to require supplemental feeds either with NG or G-tube after hospital discharge.<sup>5,8,14-16</sup> Although prior studies have suggested that most patients achieve full oral feeding, or the ability to maintain steady weight gain through oral feeding alone without the need for supplementation via alternative means after MDO,<sup>13,17</sup> there is a paucity of data investigating the immediate perioperative management of oral feeding for infants with RS undergoing MDO. In this study, we sought to further describe feeding performance and

outcomes of infants undergoing MDO at our institution with the primary outcome of time to full oral feeds after MDO. Additionally, we report preoperative oral feeding patterns, advancement of oral feeding in the immediate postoperative period, patient characteristics leading to G-tube placement after surgical intervention, and growth outcomes.

## Methods

Institutional Review Board approval from the Medical University of South Carolina was obtained for a retrospective chart review. We included children less than one year of age who were diagnosed with RS and underwent MDO at our tertiary pediatric hospital from May 2010 to December 2019. Patients who underwent MDO surgery after one year of age, had G-tube or tracheostomy placement before MDO, or had RS without a cleft palate were excluded. Patients with incomplete postoperative feeding data and those who were at full oral feeds preoperatively were also excluded.

All infants underwent a trial of conservative management before MDO including prone or side-lying positioning, nasal trumpet, and/or oxygen supplementation. A speech-language pathologist (SLP) was consulted on all patients upon admission and an individualized plan for oral feeding attempts was initiated if deemed appropriate following evaluation. If oral feeds were recommended, most infants were fed in either the side-lying or the prone position using the Medela Special Needs Feeder or Dr. Brown's Specialty Feeding System. The advancement of oral feeding attempts was individualized to the patient at the discretion of the SLP. All MDO surgeries were conducted by 2 pediatric otolaryngologists after consultation between parents and surgeons. Parental consent was obtained for all patients prior to surgery. Surgery was performed under general anesthesia. Both internal and external distractors were used. Patients remained intubated after MDO surgery for 3 to 4 days on average until the airway was predicted to be sufficiently augmented from the distraction process. Per our practice protocol, distraction was initiated following 48 h of latency at a rate of 1.5 mm per day (twice daily at 0.75 mm per distraction). Our tertiary children's hospital is staffed with SLPs dedicated to creating the best treatment plans and goals individualized to the infants included in this study. Per our institution's postoperative feeding protocol, oral feeds were initiated on 1 to 3 days after extubation which corresponds to 4 to 7 days, on average, after the initial date of surgery.

Chart review included demographic information such as sex, age at the time of MDO surgery, presence of genetic syndromes, and cleft palate. Perioperative data collected included preoperative oxygen requirement, preoperative carbon dioxide and bicarbonate values, any airway interventions, date of extubation, oxygen requirement postoperatively, and distraction time and distance. At our institution, we do not routinely obtain postoperative carbon dioxide or bicarbonate levels or complete polysomnograms unless there are concerns for obstructive sleep apnea so this information was not obtained for all patients after MDO. Feeding outcomes collected included preoperative feeding performance measured as an average percent of oral intake with respect to the child's total nutritional intake goal in the 3 days prior to MDO, G-tube requirement and age at placement, time to initial oral feeding attempts following MDO, and time to full oral feeding following extubation. We also collected weight percentiles at the time of MDO and at 1, 2, 3, 6, and 12

months postoperatively. Weight percentiles were based on 2006 World Health Organization (WHO) international growth charts.<sup>17</sup> Lastly, complications were reviewed.

All statistical analyses were performed via R (R Core Team, 2019). Means, standard deviations (SDs), and proportions summarized characteristics of the study sample. Differences in mean and proportion with corresponding 95% confidence interval for continuous and categorical variables were used to present the sample characteristics by G-tube status. A cumulative incidence plot was used to demonstrate the incidence in percentages of patients with full oral intake as measured in days after extubation. Pointwise 95% confidence intervals based on log-log transformation were used given the small sample size. Lastly, the mean weight percentile was plotted to evaluate change in percentile growth at 1, 2, 3, 6, and 12 months postoperatively.

## Results

Of the identified 40 patients, 10 patients were excluded due to MDO performed after one year of age, 6 were excluded due to procedures before MDO (3 tracheostomy, 2 G-tube, 1 tracheostomy, and G-tube), 2 were excluded due to insufficient post-operative feeding data, one was excluded due to no cleft palate, and one was excluded due to achieving full oral feeding prior to MDO. In the remaining cohort of 20 patients, 14 (67%) were male and 15 (75%) infants were discharged after MDO having reached full oral feeds without the need for G-tube placement (Table 1). The most common syndromes were Stickler syndrome and chromosomal deletions. Mean age at MDO was  $25 \pm 14.7$  days for patients requiring G-tube placement postoperatively and  $26.1 \pm 10.7$  days for patients not requiring G-tube placement postoperatively. Associated syndromes were present in 80% of patients with a G-tube versus 13% of patients in whom a G-tube was not placed. None of the patients had postoperative complications or infections in the year following MDO.

Data for children with preoperative oral feeds demonstrated that the average oral intake prior to MDO was 22.1% of individual goal feeds. For patients who did not require G-tube placement ( $n = 15$ ), the mean time to full oral feeds following extubation was  $11 \pm 5.7$  days. Of note, in the 3 infants that required the longest time to full oral feeds, the prolonged post-operative feeding course was complicated by a viral upper respiratory infection, a history of hypoxic encephalopathy, and laryngomalacia requiring supraglottoplasty. A cumulative incidence curve demonstrates the probability of patients reaching full oral feeds after extubation (Figure 1). The earliest that a patient achieved full oral feeds was 5 days after extubation. Half of the infants reached full oral feeds by 10 days and 80% of infants reached full oral feeds at 15 days after extubation following MDO.

The average weight-for-age growth curve was at the 18.7th percentile at the time of MDO using the WHO growth curve (Figure 2). Mean percentages of weight-for-age percentile were relatively decreased during the first 3 months after the procedure: 12.2th percentile at one month, 9.6th percentile at 2 months, and 11.0th percentile at 3 months after MDO. The mean nadir was at approximately 2 months postoperatively which was followed by a mean upturn in weight starting after the third month after MDO. There was a recovery to pre-operative mean weight-for-age percentiles by 6 months after surgery at the 21.2th

percentile and children continued to improve on the growth curve to 40.1th percentile at one year after MDO.

## Discussion

Over the past decades, MDO has become a well-accepted method of surgical treatment of airway obstruction in infants with RS. Following MDO, adequate oral feeding and growth is a precursor to discharge from the hospital. Although patients must be able to meet nutritional requirements by bottle and demonstrate adequate weight gain, the time frame in which infants that have undergone MDO should be allotted to achieve this milestone remains unclear. Prior studies report improvement in feeding in terms of a general timeline such as month or by one year, however, none have provided detailed information describing the perioperative feeding course in children with RS undergoing MDO.<sup>9</sup> This information is pertinent, especially as it pertains to the possibility of hospital discharge without the need for additional surgical intervention such as a G-tube. The results from the present study provide perioperative feeding data to help inform clinical decision-making and feeding expectations for multidisciplinary teams. Our results suggest that even infants with nonsyndromic RS taking on average a quarter of their goal feeds before MDO may still be able to reach full oral feeds within 2 weeks after surgery. In this cohort, the average time to reach goal oral feeds was 11 days after extubation with most (80%) infants having reached their goal feeds by 15 days. Therefore, we advocate that feeding therapists experienced in feeding therapy and in cleft and craniofacial management work closely with infants and caregivers for a full 2 weeks before consideration of G-tube placement after MDO.

Despite limited guidance from the literature, clinicians are often required to make recommendations and prepare families regarding G-tube placement in conjunction with MDO. However, the lack of information regarding perioperative feeding performance in this population makes parental counseling and the decision regarding G-tube placement challenging. Our results show that the only variable that was associated with higher rates of G-tube placement were children with syndromic RS, which is consistent with previous studies.<sup>9,18-20</sup> We found no other associated factors with children receiving G-tube placement such as preoperative blood gas levels (carbon dioxide and bicarbonate) or age at MDO. When comparing children with RS that underwent early versus late repair, Lidsky et al. found that children with feeding difficulties who underwent MDO in infancy were less likely to require G-tube placement when compared with children who received later surgical correction, though preoperative feeding difficulties or percentages of oral intake were not detailed in their study.<sup>20</sup> Our reported time interval to full oral feeds is much earlier than the previously discussed studies, which may be explained by our institution's protocols for feeding after MDO. Per our institution's postoperative protocol, infants start oral feeds on post-extubation day one to three after MDO, which may facilitate earlier times to goal feeds. The 3 patients that required additional time to reach full oral feeds each had additional circumstances surrounding their prolonged postoperative feeding course including laryngomalacia requiring supraglottoplasty, a history of hypoxic-ischemic encephalopathy and viral illness.

## Feeding

The present study offers more complete patient-level information on feeding data immediately before and after MDO. For example, in a comparison study examining outcomes after tongue-lip adhesion versus MDO, Papoff et al<sup>19</sup> reported children who underwent MDO took 44 days for full oral feeds; however, the sample size only included 9 patients, 5 of which had associated syndromes, and there is no discussion about preoperative feeding status. A systematic review of feeding and gastroesophageal reflux in children after MDO included 21 studies that did not include preoperative feeding data or reported it as PO versus alternative route such as NG.<sup>13</sup> Postoperative feeding goals were described as full oral feeds or continuation of feeding supplementation. One report included preoperative feeding status in an older cohort of 73 patients that underwent MDO but did not include information on supplemental feeds prior to MDO.<sup>21</sup> The authors reported that 90% of children with nonsyndromic RS were on an oral diet within one month after MDO; however, it is unclear whether these children also had G-tube placement or whether they were managed as an inpatient during this time.<sup>21</sup>

For RS infants requiring inpatient-level care, the initial priority is airway stabilization followed by an assessment of their oral feeding status. If an infant does not require invasive respiratory assistance, such as mechanical ventilation or continuous positive pressure, then, at our institution, the ability to start oral feeds is considered. Determining the safety, appropriateness and bottle-feeding plan involve an individualized assessment of the infant's feeding and swallowing skills by a feeding therapist, which may include SLP, occupational therapist, or nurse, specialized in treating infants with RS. A great majority of infants with RS have a cleft palate, which limits their capacity for bottle feeding with standard commercial bottles and necessitates the use of specialized compression-based bottle systems.<sup>22,23</sup> Caregivers and providers may associate preoperative feeding success with postoperative outcomes such as reduced length of stay or need for supplemental feeding via alternative routes. However, these results suggest that it is possible for infants with poor preoperative oral feeds to meet goal targets following MDO. These data provide helpful information regarding timelines for clinicians as well as parental reassurance. If the only limitation to bottle feeding is the degree of airway obstruction in an infant, the potential to reach goal oral feeds following MDO may be possible within a 2-week time frame regardless of preoperative feeding abilities. In our experience, we found that preoperative oral intake is not necessarily predictive of the need for G-tube. At our institution, G-tube placement is typically not considered at the time of MDO, especially in infants with nonsyndromic RS.

## Growth

Failure to thrive in the RS population is likely secondary to tongue base obstruction resulting in increased respiratory effort and poor oxygenation during bottle feeding.<sup>1,2,5,7,8</sup> With the resolution of upper airway obstruction, growth would be expected to steadily increase; however, a decline in growth immediately after MDO has been documented.<sup>5,7,8</sup> In a cohort of 24 patients, Li and colleagues noted a decline in weight percentile in the first 6 months followed by an accelerated growth period resulting in similar growth percentiles as their same age unaffected peers by 12 months of age.<sup>3</sup> This slowed growth rate appears to be

unique to children with RS. When comparing growth rates in children with RS to children with isolated cleft palate only, Paes et al found that children with isolated cleft palate had significantly higher growth over the first 2 years than the RS group despite similar birth weights.<sup>24</sup> The findings herein support previous studies in which long-term growth outcomes in infants with RS show initial growth velocity decreases following MDO with eventual catch-up growth by one year of age.<sup>3,13,25–27</sup> However, we acknowledge that there is a variability of profiles in infants with RS, therefore treatment should be individualized to each patient. The decline observed in growth after MDO could be attributed to increased effort with bottle feeding due to poor suction abilities due to cleft palate, caregiver's adapting to bottle feeding with specialty bottles, untreated GERD, or ongoing airway obstruction exacerbated by oral feeds. To feed successfully, infants should have minimal airway obstruction. For example, one of the infants in the study needed a supraglottoplasty for laryngomalacia to relieve multilevel airway obstruction. Once this was addressed, this infant achieved full oral feeds. We did not obtain postoperative blood gas levels to assess for ongoing airway obstruction that could lead to increased respiratory effort and caloric expenditure. A prospective study design could further examine postoperative blood gases in relation to feeding outcomes. Finally, distraction removal, which typically takes place 6 weeks after the active distraction phase is complete, may also slow steady growth. This additional surgery could contribute to poor weight gain due to NPO status prior to surgery or if the child experiences pain afterward, possibly leading to a lapse in baseline feeding status.

### Limitations

The limitations of this investigation are secondary to the retrospective study design and smaller sample size given the low prevalence of children with RS. The results represent a cohort from a single tertiary academic center and may not be generalizable to other regions or institutions. For example, not all institutions are staffed with feeding therapists trained to assess feeding skills and provide expertise in perioperative feeding management in the special population of RS and infants with a cleft palate. Our institution has an accredited craniofacial team with providers and SLPs that are familiar with the care of infants with RS needing MDO, which could facilitate faster times to full oral feeds. Other institutional protocols may wait until the distraction process is complete to initiate bottle feeding postoperatively due to concerns of jaw immobility,<sup>28</sup> which may lead to longer times to full oral feeds after MDO. All the infants included in this review had a cleft palate, and we therefore used a specialty cleft nurse which facilitates the expression of milk or formula using compression alone and bypassing the suction mechanism. In addition, the temporomandibular joint remains unaffected postoperatively after MDO, thereby preserving the mobility of the jaw to perform compression of a specialty bottle for infants with cleft palate. Further, while we recognize that GERD is a contributing factor to feeding difficulties, this information was not included following our initial chart review as we were not certain about the reliability of the diagnosis given the lack of consistent formal diagnosis of GERD with the gold standard impedance probe testing. Lastly, a selection bias may have affected the outcomes of the study in that we excluded children with preoperative G-tube placement or tracheostomies, thereby excluding infants with potentially severe sequelae of RS. Still, many of the children with G-tube or tracheostomies were transferred to our institution for MDO. We recognize that some institutions place a G-tube at the time of MDO and so may

have very different outcomes. A larger sample size and prospective design would be needed to corroborate the present findings.

## Conclusion

This study describes perioperative feeding performance in infants with RS who underwent MDO. These data can provide helpful descriptive and prognostic information for clinicians counseling families on feeding outcomes post-surgery. Although oral feeding prior to MDO is thought to be beneficial, our findings demonstrate that infants with even low preoperative oral intake, without requiring a procedural intervention prior to MDO, can still achieve full oral feeding goals within 2 weeks after MDO. This may help inform clinicians with an expected timeline to work on oral feeds and discussion of possible G-tube placement tailored to the individual patient. Lastly, these results support previous data that infants require close monitoring of weight after MDO with eventual catch-up growth. To strengthen these findings, a larger, multicenter randomized controlled trial is needed to determine predictors for infants that require G-tube placement.

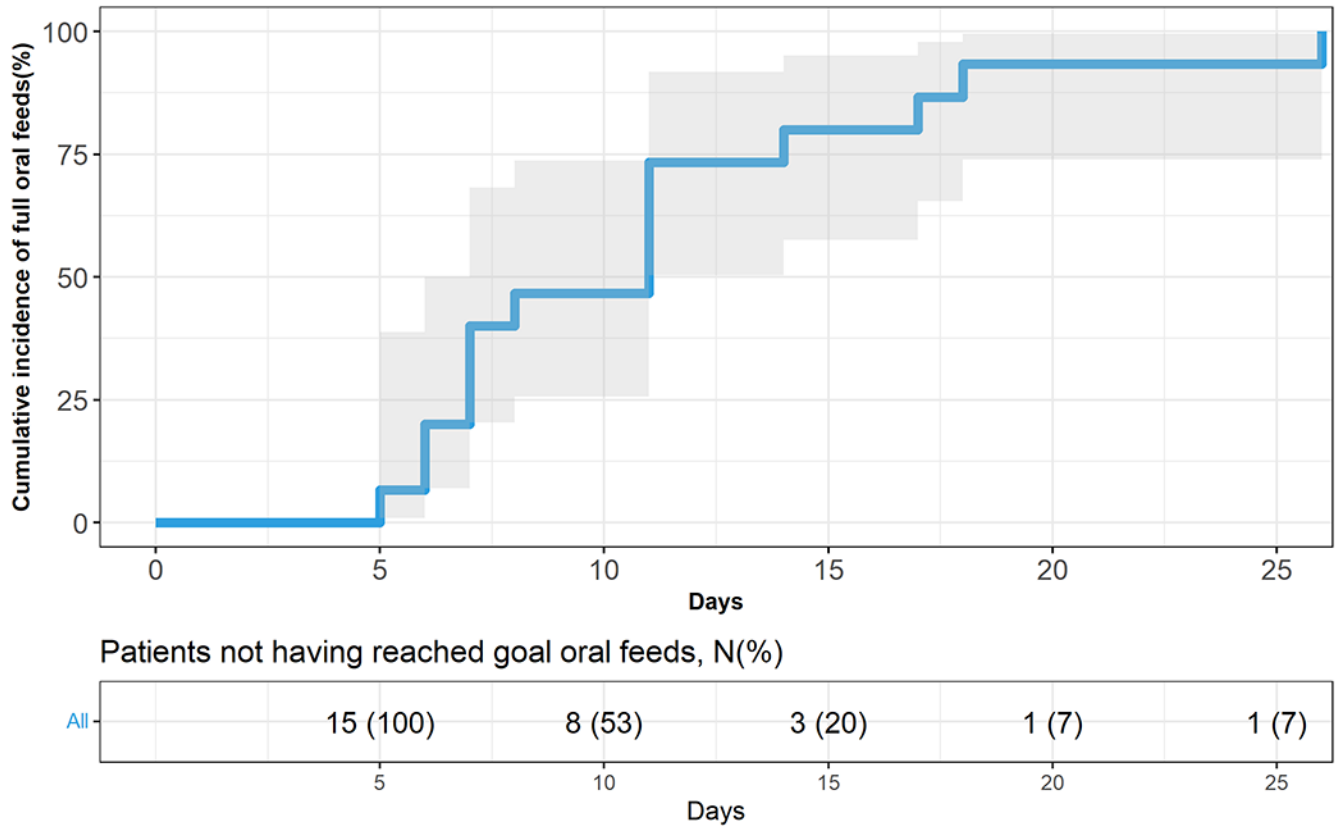
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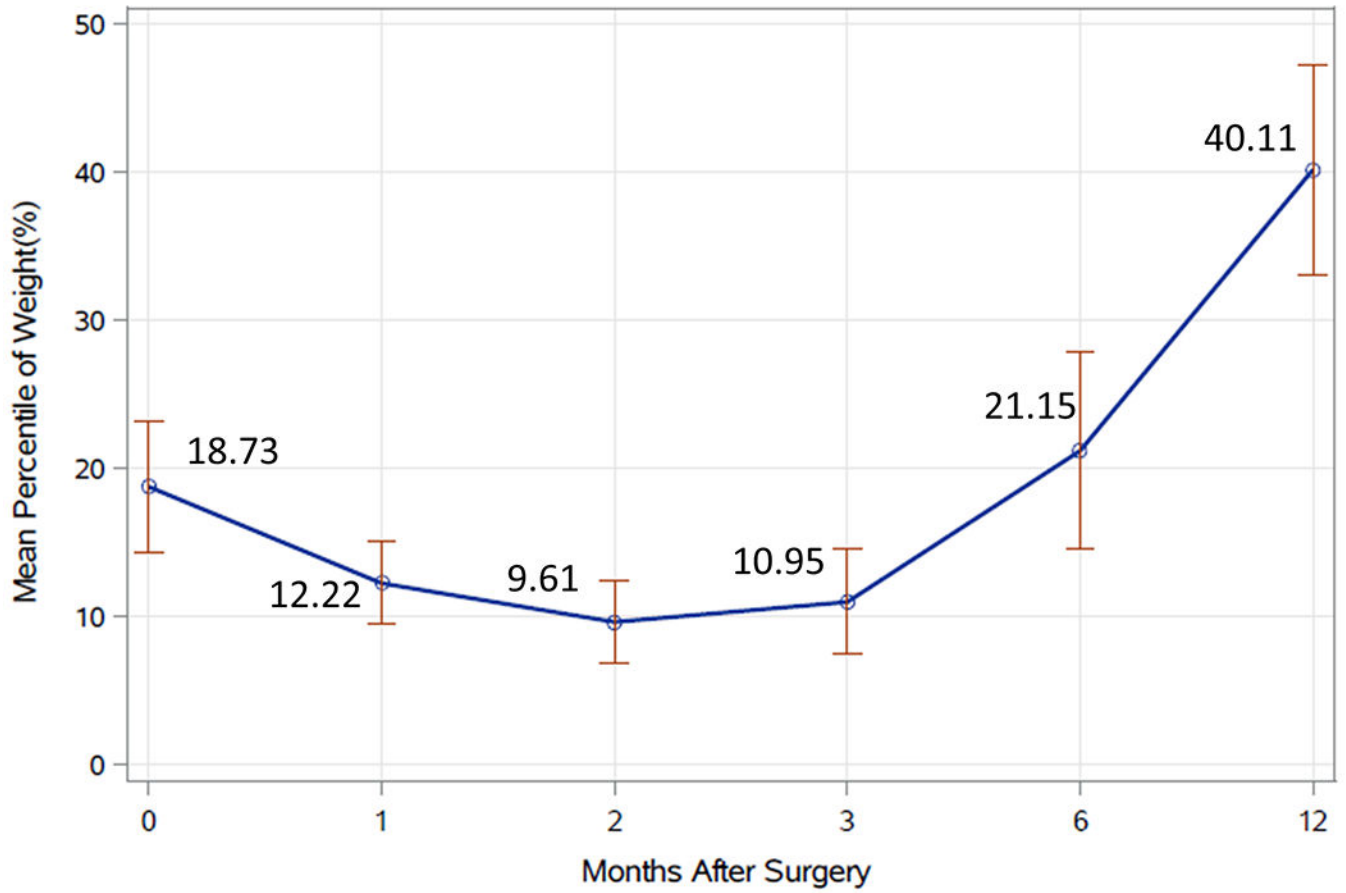
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**Figure 1.** A cumulative incidence curve demonstrating the probability of full oral feeds after extubation following distraction osteogenesis.



**Figure 2.**  
Mean weight-for-age percentile relative to time after mandibular distraction osteogenesis.

**Table 1:**

Patient characteristics of neonates with Robin Sequence that underwent mandibular distraction osteogenesis stratified by receipt of gastrostomy tube.

Characteristic	G-Tube (N=5) N (%) or mean (SD)	No G-Tube (N=15) N (%) or mean (SD)	Total (N=20) N (%) or mean (SD)	Difference in Means/ Proportions <sup>†</sup> (95% CI)
<b>Gender</b>				-0.1 (-0.5, 0.3)
Male	4 (80%)	10 (67%)	14 (70%)	
Female	1 (20%)	5 (33%)	6 (30%)	
<b>Age at time of MDO (days)</b>	25.0 (14.7)	26.1 (10.7)	25.8 (11.4)	1.1 (-16.8, 18.9)
<b>Birthweight (g)</b>	3097.4 (492.1)	3128.3.4 (483.6)	3120.6 (472.8)	30.9 (-571.1, 633.0)
<b>Gestational Age</b>	38.1 (1.2)	38.4 (1.0)	38.3 (1.0)	0.36 (-1.1, 1.8)
<b>Distraction Time Course (days)</b>	10.1 (1.7)	11.3 (1.9)	11.0 (1.9)	1.2 (-0.8, 3.3)
<b>Bicarbonate Level (mEq/L)</b>	30.2 (4.1)	30.4 (2.7)	30.4 (3.0)	0.2 (-4.8, 5.2)
<b>CO2 Level (mmHg)</b>	50.0 (10.2)	48.9 (6.4)	49.2(7.2)	-1.1 (-13.5, 11.3)
<b>Syndromic</b>				-0.6 (-1.0, -0.2)
Yes	4 (80%)	2 (13%)	6 (30%)	
No	1 (20%)	13 (87%)	14 (70%)	

CO2 = carbon dioxide; G-tube = gastrostomy tube; MDO = mandibular distraction osteogenesis

Values are n (%) or mean (SD)

<sup>†</sup>Difference in means were used for comparing receipt of G-tube by patient characteristic except for sex and syndrome status which was described by difference in proportions.