

Feeding Conjoined Twins With Suspected Milk Protein Allergy

Jennifer R. Bathgate

ICAN: Infant, Child, & Adolescent Nutrition published online 12 July 2012

DOI: 10.1177/1941406412454293

The online version of this article can be found at:

<http://can.sagepub.com/content/early/2012/07/12/1941406412454293>

Published by:



<http://www.sagepublications.com>

Additional services and information for *ICAN: Infant, Child, & Adolescent Nutrition* can be found at:

Email Alerts: <http://can.sagepub.com/cgi/alerts>

Subscriptions: <http://can.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

>> [OnlineFirst Version of Record](#) - Jul 12, 2012

[What is This?](#)

Feeding Conjoined Twins With Suspected Milk Protein Allergy

Jennifer R. Bathgate, MPH, RD, CSP, LDN

Abstract: *Conjoined twins are very rare and present significant feeding challenges in infancy because of their surgical and medical needs. This case study presents the nutritional history in a short life of a set of twins born at the University of Illinois, Chicago.*

Keywords: conjoined twins; enteral feeding; bolus feeds; tolerance

The prevalence of milk protein allergy in infants may be about 2% to 5% in formula-fed infants.¹ Symptoms usually manifest as gastrointestinal (GI) intolerance, such as diarrhea (possibly blood tinged) or vomiting. Births of conjoined twins are even more rare than milk protein allergy, occurring only once in 50 000 to 100 000 live births according to various surveys.² Overall, newborn survival rate is somewhere between 5% and 25%,² and separation is a very serious decision. A pair of thoracopagus* male twins³ was born at

*Definition: Twins united face-to-face from the upper thorax to the umbilicus, sharing the chest wall. The union always includes the heart, even if it is joined by only a single vessel and often includes a common liver and intestines. The pelvises are not united, and the twins have a total of 4 arms and 4 legs. This occurs in about 40% of conjoined twins.

the University of Illinois Medical Center at Chicago on March 31, 2010, and spent the next 498 days challenging the medical team. Initial nutritional management was fairly straightforward, considering their complex medical issues, but there were a few unexpected bumps along the road.

The twins were born full term and weighed 4600 g. Twin A had a good strong cry, but Twin B was weaker, resulting in the need to intubate both that same day (Table 1). A cardiac echogram demonstrated complex congenital heart defects, including a shared heart with

On day of life (DOL) 3, the twins were started on total parenteral nutrition (TPN), and on DOL 4, conservative bolus feeds of standard term formula were introduced. Feeds advanced without issue until DOL 24, when Twin B had multiple stools, one noted to be bloody. On DOL 26, both twins had multiple episodes of emesis. The infusion rate was slowed and volume decreased but without improvement, so the physicians changed them to soy formula on DOL 29. On DOL 30, at 45 mL every 3 hours (720 mL, 480 kcal, 12 g protein), no fur-

“Births of conjoined twins are even more rare than milk protein allergy, occurring only once in 50 000 to 100 000 live births according to various surveys.”

a single atrium. They also had a shared liver and were born with a mild omphalocele. The GI system was imaged, showing separate colons, but the remaining loops of bowel were difficult to distinguish. Their mother had been counseled about the twins' poor prognosis beginning several months before their birth, and separation was discussed with multiple specialists, but because of the shared heart and liver, separation was deemed impossible.

ther emesis was reported. They remained on this regimen until DOL 45, when they were made NPO (nothing by mouth) for a planned tracheostomy surgery. The surgery was without any reported difficulty, and they returned to the neonatal intensive care unit following surgery. There were some mechanical concerns (tube positioning and significant air leak) that prevented the soy formula feeds from being resumed for the next 48 hours after surgery (Table 2).

DOI: 10.1177/1941406412454293. From Children's Hospital of the University of Illinois, Chicago, IL. Address correspondence to Jennifer R. Bathgate, MPH, RD, CSP, LDN, Children's Hospital of the University of Illinois, 1740 W Taylor St, Chicago, IL 60612; e-mail: jrbathgat@uic.edu.

For reprints and permissions queries, please visit SAGE's Web site at <http://www.sagepub.com/journalsPermissions.nav>.

Copyright © 2012 The Author(s)

Table 1.**Active Problem List (Both Twins)**

Thoracopagus conjoined twins sharing heart and liver
Deemed inseparable by all experts consulted to date
Severe cardiac anomaly (common atrium, Ventricular Septal Defect, double outlet ventricles)
Cardiac/Respiratory failure on medication
Ventilator dependent, status-post tracheostomy
Milk protein allergy
Healed omphalocele
Desaturations: more recently increasing in the vent setting support August 1, 2011
Specific twin-A problems
Oliguric, decreased renal function
Specific twin-B problems
Better renal function as compared with twin A
Hypoplastic lungs
Seizures
Cerebral infarcts ×2 (June 2010)

They transferred to our care in the pediatric intensive care unit on DOL 75, weighing 8185 g. TPN was providing 745 kcal (99/kg) with 3 g/kg each of fat and protein, meeting assessed nutrition needs. Since birth, the twins had gained a total of 2900 g, or 39 g/d. Goal for age in a healthy infant is 25 to 35 g/d, with no standards available for conjoined twins. TPN was continued, and soy feeds were resumed at 3 mL/h via a nasogastric tube for each twin. We advanced the feeds cautiously because of the reports from the nursery of their instability but were able to discontinue TPN by DOL 80 because they achieved their fluid goal. Labs were monitored, which were unremarkable, along with weight. The boys had no significant GI issues, generally stooling a few times each day with good consistency and no emesis. Weight gain continued, and feeds were gradually titrated up over several weeks.

In January, rice cereal was added to their formula because they were now 10 months old with their sole source of nutrition being infant formula. Vitamin and mineral needs of conjoined twins must be individualized based on specific anatomy, but obviously, normal, healthy

babies would be eating a variety of foods by this age, and therefore, the cereal was added to increase intake of micronutrients such as iron. Rice cereal is added in our unit with good results in many exclusively tube-fed infants. It was well tolerated with the twins' bolus feeds, and they continued to grow well. They were also doing well from a respiratory standpoint, tolerating several hours each day of ventilator "sprints" or transitions to trach collar. We periodically discussed attempting oral feedings, but primarily because of their positioning, this was never successful. The twins spent most of their time lying on their sides, only able to sit upright with multiple caregivers assisting, so oral feeding attempts were not safe.

The twins were switched on DOL 364 to a standard pediatric formula, but both immediately had both emesis and diarrhea. They were changed back to the soy infant formula for the weekend to allow their birthday celebration to continue. It took them a few days to recover completely, and by DOL 368 they were back on full strength soy infant formula feeds at the previous volume. We discussed them daily on medical rounds, and the team agreed on DOL 370 to try

a partially hydrolyzed pediatric formula. The response, again, was immediate, with episodes of diarrhea and emesis, so they were again restarted on infant formula feeds. At this point, it seemed evident that the lack of tolerance was likely a result of a milk protein allergy because the hydrolyzed formula did contain whey protein.

The choice of soy formula in the nursery was fortuitous because it is generally accepted practice that "soy protein-based formulas are no less allergenic than are cow milk protein-based formulas."⁴ The American Academy of Pediatrics recommends using extensively hydrolyzed formulas in infants with suspected milk protein allergy, but they had thrived on the soy formula chosen to replace their standard formula early in life. It was not until nearly 2 months later, at nearly 14 months of age, when a final attempt to change from soy to a more age-appropriate formula was made, this time using a completely elemental formula. The team was originally hesitant to change formulas because of the perceived cost, but the price difference between infant formula and elemental was found to be less than \$10 per month. The team finally agreed to a final attempt to change formula, initially starting with the pediatric formula concentrated to infant formula concentration (20 kcal/oz). They tolerated the elemental formula without any issue, so they advanced a week later to formula concentrated to 25 kcal/oz with a slightly lower volume.

At the time, their feeds provided 780 mL, 840 kcal (54/kg), and 26.5 g protein (1.7/kg) in 120 mL every 4 hours, and their weight was 15.5 kg. The formula was fortified with rice cereal, 30 mL now in each of the 6 feeds/d, which the RNs felt was a better consistency; there had been complaints that the unfortified formula was too thin and caused increased secretions for suctioning. Because the boys spent very little time upright as a result of their physiology, thicker formula was thought to be a benefit. Rice cereal is relatively innocuous and provides an additional source of kilocalories and modest iron intake, so it was decided that there was no problem continuing the added rice.

Table 2.

Nutrition Time Line

DOL 4	TPN	4350 g
DOL 5	Introduced bolus feeds (Enfamil 20 kcal/oz)	4370 g
DOL 14-16	TPN d/c, advancing volume	5396 g
DOL 24	Bloody stools/Emesis	5326 g
DOL 29	Continued emesis, changed formula (Prosobee)	5372 g
DOL 30	No emesis, full feeds, Prosobee 20 kcal/oz	
DOL 37	Tolerating feeds well (full feeds = 45 mL every 3 hours each)	5560 g
DOL 45	NPO since midnight for tracheostomy surgery	6070 g
DOL 47-63	Resume feeds with intermittent tolerance/Respiratory distress	
DOL 64	Twin B has a seizure, found to have a stroke	
DOL 66	Feeds restarted at 10 mL every 3 hours	7550 g
DOL 68	Feeds tolerated, begin advancing by 5 mL every 12 hours	
DOL 72	Desaturations, emesis, NPO	
DOL 75	Transfer from Intermediate Care Nursery to PICU, first seen by RD; suggested resume enteral feeds (continuous)	8.2 kg
DOL 77	On TPN and 7 mL/h Prosobee 20 kcal/oz	
DOL 83	d/c TPN; full feeds of Prosobee 20 at 25 mL/h	8.7 kg
DOL 91-153	Feeds advanced for weight gain	10.4 kg
DOL 181	Feeds changed to 60 mL every 2 hours, then 90 mL every 3 hours on October 6	12.1 kg
DOL 223	Feeds changed to 130 mL every 4 hours	13.1 kg
DOL 272	Feeds continue, added rice cereal 20 mL once daily	13.8 kg
DOL 364	Feeds changed to Pediasure 120 mL every 4 hour	14.6 kg
DOL 365	Tube Feeding not tolerated (vomiting / diarrhea); changed to Pedialyte	
DOL 366	Feeds back to Prosobee at 35 mL/h	
DOL 370	Trial of Peptamen Jr 120 mL every 4 hours	
DOL 371	TF not tolerated (V/D): changed back to Prosobee	
DOL 413	Prosobee 20 kcal/oz at 150 mL every 4 hours	
DOL 420	Elecare 20 kcal/oz at 150 mL every 4 hours; tolerated	
DOL 427	Changed to Elecare 25 kcal/oz at 120 mL every 4 hours + rice cereal	
DOL 462	Increasing to 125 mL every 4 hours	14.7 kg
DOL 497	Continue Elecare 25 kcal/oz at 125 mL every 4 hours	17 kg
DOL 498	Death: cardiorespiratory failure	

Abbreviations: TPN, total parenteral nutrition; NPO, nil per os (nothing by mouth).

Unfortunately, whereas the year had started fairly well for the twins from a respiratory standpoint, after a few

months, their single heart was no longer able to support them. They were both back on ventilators, and talk of sending

them home, which had seemed possible earlier in the year, diminished, with the team losing hope that they would ever leave the hospital. They continued to grow and thrive from a nutrition standpoint, achieving a final measured weight of 17.2 kg on DOL 495. However, their organs were stressed, and as had been suspected since birth, their heart began to fail. Their clinical status deteriorated fairly quickly over the last 2 weeks of their lives, until finally, on the evening of DOL 497, they had increased desaturations with episodes of bradycardia. Because of their anatomy, a normal code with chest compressions or defibrillation was impossible, but a code was conducted for approximately an hour until it was determined that the boys had died.

Their mother, although understanding from before they were born that the boys were up against tremendous odds for survival, was understandably heartbroken, as was the staff of the ICU. From a medical perspective, they had not been expected to survive to 16 months old, although the team kept up hope that they might, somehow, overcome those odds. Despite all our best efforts, unfortunately, they eventually succumbed to their physiological weaknesses. It is rare to have an opportunity to participate in the care of such interesting and challenging individuals, and I will always be thankful for the small role I played in their short lives. ■

References

1. Brill H. Approach to milk protein allergy in infants. *Can Fam Physician*. 2008;54:1258-1264.
2. University of Maryland Medical Center. http://www.umm.edu/conjoined_twins/facts.htm. Accessed February 20, 2012.
3. Quigley C. *Conjoined Twins: An Historical, Biological and Ethical Issues Encyclopedia*. London, UK: McFarland; 2003:4.
4. Kleinman RE, ed. *Pediatric Nutrition Handbook*. 6th ed. Elk Grove Village, IL: American Academy of Pediatrics; 2009.