omphalocele, gastroschisis, congenital diaphragmatic hernia, and myelomeningocele.

Given the known feeding challenges among infants with T13/T18, even in the absence of gastrointestinal anomalies, gastrostomy tube placement is one of the more common surgical procedures considered in the neonatal period.[5,44] Gastroesophageal reflux, also common among infants with T13/T18, may complicate decision making about the approach to feeding these infants.[16] Although this might be considered early in the hospital course in coordination with other surgeries, infants can be supported with nasogastric feedings until later in the hospital stay while other medical issues are addressed; discharge home with nasogastric (or nasojejunal) feedings can be considered if appropriate support is in place, with consideration for transition to g-tube feedings if longer-term survival becomes more likely. Alternatively, withdrawal or withholding of medically provided nutrition may be offered in limited circumstances and is often done with involvement of an institutional ethics committee.

Other surgical procedures might be indicated with the goal of providing comfort for the infant and moving care forward, such as bronchoscopy for the assessment and possible treatment of airway issues that are more prevalent in patients with T13/T18,[16,45] or a ventriculoperitoneal shunt if an infant has symptomatic severe ventriculomegaly. The decision to expose an infant to surgical intervention in the neonatal period—urgently or electively—should balance the risks of causing harm with the benefits of surgery, given the higher surgical morbidity and mortality in infants with T13/T18. Families should be counseled that surgical intervention in this population is associated with prolonged hospital stay and increased risks with anesthesia and intubation.[45,46]

CONTINUED CARE IN THE NICU AND BEYOND

Five to forty percent of infants with T13/T18 survive to 1 month of age, depending on their comorbid conditions, level of intervention, gestational age, sex, as well as other factors that are not yet well understood.[46–50] When parents desire all available interventions and the infant survives the first few days of life, many additional decisions will likely need to be made. For the 5% to 15% of infants who survive to 1 year of age, evidence suggests that they could survive for years, even occasionally into their 20s, typically utilizing some degree of medical and/or technological support.[47] There is currently insufficient evidence to differentiate long-term survivors prenatally from those with early mortality, making prognostication challenging, although mosaicism likely provides some survival benefit, and multiple or severe anomalies and prematurity are known to increase the risk for early mortality.[51]

A small proportion of children with T13/T18 will survive the initial neonatal period but require ongoing mechanical ventilation despite maximal medical interventions, often because of a combination of central apnea and airway anomalies, which are much more common in this population.[16] For families who wish to continue LSIs, open and clear discussions about potential placement of a tracheostomy tube ideally begin early in the hospital course, to support informed decision making. The significant lengthening of the hospital stay, need for home nursing care, and risks associated with long-term home ventilation must be carefully explained to these families, as it is with other children who meet indications for tracheostomy. Additionally, the baseline increased surgical risk for children with T13/T18 must be discussed during the consent process, as well as the mixed data around anticipated benefits of long-term mechanical ventilation in this population.[36] Epilepsy-related apnea can occur in this population, so consultation with pediatric neurology, use of electroencephalography, and antiepileptic agents should be considered for those infants exhibiting apnea potentially consistent with seizures or those with central nervous system abnormalities known to increase risk for seizures, after discussion of the risks and benefits with parents.[52,53]

Discharge planning for infants with T13/T18 must be individualized to the infant's specific medical needs, goals of care, and practical considerations such as distance from relevant specialists and family and community resources. To optimize care for this medically complex population, it is important to ensure a smooth transition from the NICU to an outpatient medical home, so the family will continue to have support, as there are likely to be new circumstances that may require ongoing discussions about goals of care.[54] Guidelines for this population were published by Kepple et al, which offer detailed screening recommendations to be used throughout childhood.[5,6] Generally, infants with T13/T18 should receive routine anticipatory guidance and childhood vaccinations.[16] Routine health maintenance, including vaccinations and health screenings, should not be withheld solely on the basis of a diagnosis of T13/T18 and should be based on the family's goals of care. Condition-specific growth curves are available in print[55] as well as online through Support Organization for Trisomy, or SOFT.[56] For those practicing obstetric and neonatal care, there are specific growth curves for 22 weeks' gestation through term.[57] For infants who have not had access to nirsevimab, palivizumab should be considered for any patients with T13/T18 during respiratory syncytial virus season, even if they do not meet respiratory or cardiac criteria, if there is evidence of decreased ability to clear secretions because of their increased risk for complications.[5,16,58]

Important components of discharge planning are described in Table 5. The outpatient plan should be reviewed and clarified regularly before presentation in an acute crisis whenever possible, and provided in writing to the family, in case the parents need to call for emergency