CE Ethics Series

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# Caring for the Infant With Trisomy 18

## *The Bioethical Implications of Treatment Decisions on Nurses*

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Infants born with trisomy 18 have multiple congenital abnormalities and shortened life spans. Advances in medical and surgical technology have provided some families with choices to optimize care. Given the differing outcomes that exist for infants born with trisomy 18, several questions are raised that carry weighty ethical implications. A case study will be discussed to illustrate the ethical dilemmas that nurses encounter when caring for infants with Trisomy 18. These dilemmas include the following: (1) When is it ethical to limit options offered for medical interventions? (2) Who makes decisions when options for medical interventions are considered futile? (3) What principles guide decisions about care? (4) What options are available to nurses when they do not agree with family members about suffering?

**KEY WORDS**

bioethics, decision-making, futility, trisomy 18

Trisomy 18 is a genetic disorder in which infants are born with multiple congenital anomalies that require parents and health care providers to discuss options on how to proceed with care. Families and providers are confronted with decisions regarding whether to pursue invasive procedures. This is often a source of stress for all those caring for the infant, including nurses. Ethical dilemmas may arise that necessitate thoughtful consideration of the benefits and risks of certain interventions. Even when the options may seem clear, not everyone will agree on what is in the infants' best interest. The following case study illustrates the ethical dilemmas that can occur.

## CASE STUDY

Monica was prenatally diagnosed with trisomy 18. After meeting with the perinatal palliative care team, and given the option to either terminate or continue with the pregnancy, her parents, Sarah and Sam, decided to proceed with the pregnancy. They were told that their daughter would likely die within the first days to weeks of life. They were also told that there was a small chance that she might survive the initial "newborn period" and that they would have the support of the palliative care team and could make the decision to go home with hospice care. They also met with the genetics counselor and social worker and were given the opportunity to meet another parent who also had an infant with trisomy 18. They declined to speak with other parents at that time.

Monica was born at 35 weeks gestation. In the delivery room, she had notably poor respiratory effort. Monica was small for her gestational age and she had typical features of an infant with trisomy 18, including an abnormally shaped head, micrognathia, clenched fists, and overlapping fingers. Immediately after birth, she was transported to the neonatal intensive care unit, an intravenous line was placed for hydration, and she was intubated with ventilator support for poor respiratory effort. An echocardiogram revealed that she also had a congenital heart defect, but not one that would need immediate surgical intervention. A meeting was scheduled with Monica's primary neonatal care team soon after her birth. Sarah and Sam were told there was a good chance their daughter would not survive without a ventilator and she would need a nasogastric tube (NGT) for enteral feeds. Her parents were given 2 options on how they wold like to proceed: 1) remove the ventilator and provide supplemental oxygen via a nasal cannula for comfort or 2) extubate with the option to reintubate if necessary to allow the family more time with a plan for a compassionate extubation.

Sarah and Sam were in their early 40's and had waited to have a child. This was their first pregnancy. Sam worked as an engineer and had his own consulting business and Sarah managed the financial aspects of Sam's business and worked part-time as a real estate agent. Sam planned to return to work shortly after the birth and Sarah planned to stay home and eventually go back to work part-time.

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The authors have no conflicts of interest to disclose.

DOI: 10.1097/NJH.0000000000000095

Sarah's parents lived nearby and were a great support for Sarah and Sam; they both had siblings with children and worried about what to tell them when Monica was born and was not a "normal baby." They did not have any specific religious affiliation but did have a "holistic" approach to care. They understood the poor prognosis and wanted to focus on Monica's comfort and quality of life (QOL). They opted for extubation with supplemental oxygen to be given via a nasal cannula and did not want her to be reintubated. Sarah and Sam agreed to a do not attempt resuscitate (DNAR)/do not intubate (DNI). Monica's ventilator was removed after 1 week. She did not die. Instead, Monica survived the extubation and after a few days went home with supplemental feeds via an NGT and 2 L of oxygen via nasal cannula. The palliative care team met continually with Sarah and Sam and the decision was made to initiate home hospice services to support the parents and help with symptom management at home. An out-of-hospital DNAR/DNI was signed.

Monica did well at home, and her parents reported that hospice services were helpful and that Monica was a happy baby, despite not sleeping well and, at times, not tolerating feeds. Then, at 5 months of age, Monica began having episodes of transient dyspnea at home. Her pediatrician ordered a chest radiography, where she was noted to have a left diaphragmatic eventration. She was admitted to the hospital to discuss all options, including surgical repair of the hemi-diaphragm, and again met with the palliative care team. Sarah and Sam had always been in agreement about their decisions regarding Monica's care and continued to support each other in the decision-making process. Together, they decided not to pursue a diaphragmatic plication because the uncertainty around its benefit for Monica was too great. They also were worried about general anesthesia and the possibility that Monica would not be able to wean off the ventilator. They wanted to explore all other options, including noninvasive measures (ie, continuous positive airway pressure [CPAP] or bidirectional positive airway pressure). Monica's parents felt that bidirectional positive airway pressure was too constricting but felt that Monica tolerated CPAP well; discharge was planned for the following week, again with hospice care in place. At that point, however, Sarah and Sam chose to revoke the DNAR/DNI. After thoughtful consideration and conversations with the palliative care team, they decided they would want her intubated in case the cause was reversible (ie, a respiratory infection). However, they stated that if Monica's condition and QOL declined, they would reconsider the DNAR/DNI. They both stated they would never want Monica to undergo a tracheostomy.

At home with CPAP, Monica was having worsening irritability related to reflux and intolerance of feeds. She was still not sleeping well and began to struggle with ongoing constipation. Despite several attempts to manage this at home with medications, Sarah often felt that the medications for constipation caused excessive cramping and discomfort for Monica, and she was intermittently admitted to the hospital for severe constipation. Monica was now 10 months old, and Sarah and Sam wanted her to be evaluated for a gastrostomy tube (GT) and diaphragmatic plication, in an attempt to improve her respiratory function. During the admission process, Sarah and Sam told the team that in the event Monica had a sudden cardiac arrest, they would not want chest compressions (DNAR) but would want cardiac medications and intubation. They understood that the surgical procedure for Monica was not without risks and would require general anesthesia and intubation, and they were worried about the possibility that Monica would not be able to be extubated. Some of the nurses caring for Monica were concerned about Sarah and Sam's decision to pursue surgery for Monica, and they spoke with the palliative care team about their angst and the possible effect that it would have on their ability to care for Monica. At this time, the hospital ethics committee was consulted to provide guidance to the teams caring for Monica. The committee concluded that the decisions her parents were making were reasonable. Monica's diaphragm was plicated and a GT was placed. She was extubated within 36 hours to CPAP but soon developed respiratory failure and required reintubation.

A week later, and with Monica doing well on minimal ventilatory support, the team made another plan to extubate. Sarah and Sam felt that this was too soon and asked them to give Monica another 24 hours on CPAP. The nurses caring for Monica continued to express their concerns about the outcome of these interventions, but they continued to provide good care for Monica and to respect Sarah's and Sam's wishes. Later that week, Monica was extubated, placed on CPAP, and again developed respiratory distress. Sarah and Sam still felt that this was caused by the general anesthesia, which they considered to be a "reversible cause," and wanted Monica to be reintubated with more time to recover. The nurses believed Monica was suffering with prolonged intubation.

The neonatal care team, together with the palliative care team, planned a family meeting with Sarah and Sam to readdress their goals. Sarah and Sam felt that Monica had survived much longer than anyone expected and had a good QOL at home and that she would return to her presurgical state of functioning once she fully recovered from the effects of the anesthesia. Sarah and Sam mentioned during the meeting that, in the past, they did not want a tracheostomy as they felt that being "permanently attached to a ventilator" was not the life they wanted for Monica. However, they had begun to talk with other families with children with trisomy 18 and learned that many families have happy children who have a good QOL, even after a tracheostomy,[1] and wanted to revisit this option. Sarah and Sam assured the team that Monica was stronger than anyone ever imagined and had made it this far and they will not "give up on her now." They believed that given enough time, they would be able to wean Monica from the ventilator and they could live with a tracheostomy if she did not require continuous ventilatory support. The parents asked the team to "look beyond" Monica's chromosomal diagnosis and allow her to have the same options for living as any other child. The team felt it would be unfair to exclude her trisomy 18 diagnosis because euploidy is a known predictor of perioperative morbidity and mortality.

The nurses believed that the family was stuck in "doing more" and not wanting to accept the normal trajectory for an infant with trisomy 18. Although they understood that, up until that point, Monica had lived longer than expected, they now felt Monica was spending more time in the hospital than at home, which did not give her good QOL. The nurses raised their concerns to the team as to why so many options were being offered to the parents for surgical intervention.

**TABLE 1 Characteristics of an Infant With Trisomy 18**

| |
|---|
| Clenched fist with overriding fingers |
| Feeding intolerance, often requiring enteral nutrition |
| Microcephaly |
| Rocker-bottom feet |
| Short sternum |
| Skin redundancy |
| Small fingernails |
| Small mouth |
| Underdeveloped thumbs |
| Weak cry |
| Wide fontanel |

*Source: Cereda and Carey[2] and Pont et al.[8]*

## OVERVIEW OF TRISOMY 18

Trisomy 18, also known as Edwards syndrome, is a disorder that occurs because of the presence of an extra chromosome 18; thus, individuals with this disorder have 3 copies of chromosome 18, instead of the usual 2 copies. The severity of the disease and its clinical manifestations (Table 1) can be determined, in part, based on the cellular pattern of the genetic variation (ie, full, partial, or mosaic presentation); however, it is often difficult to predict exactly how severe a case will be and how well the infant will do over time. Because of the presence of several life-threatening and fatal conditions (Table 2), many infants born with trisomy 18 die before birth or within their first weeks to months of life.[2] Fifty percent live longer than 1 week,[2,3] 5% to 10% live past their first birthday, and individual cases have been reported of children living into toddlerhood and some even into adolescence, albeit all with myriad comorbidities due to multiple anomalies.[3] It is known, however, that infants with trisomy 18 have low survival rates and an increased risk of death in the first year of life.[4] Mosaic trisomy 18, in which the extra copy of chromosome 18 occurs in only some of the body's cells,[3] occurs in about 5% of all cases and has a wide phenotypic presentation, with survival time ranging from days to several years. The severity of the mosaicism depends on the type and number of cells that have an extra chromosome.[3,5] This is important because it affects the clinical course, medical management, and options available for each affected individual.[5]

Trisomy 18 is the second most common type of trisomy,[6] with an estimated prevalence of 1:3000 to 1:10 000 live births. It is characterized by psychomotor and growth retardation and cardiac, renal, respiratory, and nervous systems abnormalities.[2,7,8] After birth, infants with trisomy 18 often experience episodes of apnea, feeding issues, difficulty coordinating suck and swallow, and upper airway obstruction. They also have a range of structural abnormalities that may result in a number of complications (Table 2). Studies have shown that if the infant survives beyond the first several weeks, chances of surviving beyond their first year increases to approximately 5% to 10%.[1,9,10] Factors contributing to increased mortality include prematurity less than 32 weeks' gestation, early apnea, and severity of the cardiac anomaly.[11]

## BIOETHICAL DILEMMAS

This case raises several bioethical dilemmas, not only for the family/parents but also for the health care team members, including nurses, caring for Monica and her parents, Sarah and Sam. (1) When is it ethical to limit options offered for medical interventions? (2) Who makes decisions when options for medical interventions are considered futile? (3) What principles guide decisions about care? (4) What options are available to nurses when they do not agree with family members about suffering?

### When Is It Ethical to Limit Options for Care?

One of the most challenging ethical dilemmas in neonatal medicine is whether to offer aggressive resuscitative and surgical treatment for infants diagnosed as having a poor prognosis because of genetic anomalies, such as trisomy 18. Trisomy 18 is associated with many congenital anomalies

**TABLE 2 Systems Affected by Trisomy 18**

| System | Defect |
|---|---|
| Cardiac | Aortic and/or pulmonic valve disease, coarctation of the aorta, dextrocardia, patent ductus arteriosus, pulmonic stenosis, septal defects, tetralogy of Fallot, transposition of the great arteries, valve leaf abnormalities |
| Central nervous system | Agenesis of corpus callosum, cerebellar hypoplasia, facial palsy, hydrocephalus, meningomyelocele, polymicrogyria, spina bifida |
| Craniofacial | Choanal atresia, cleft palate, lowset ears, micrognathia |
| Gastrointestinal | Esophageal atresia with tracheal-esophageal fistula, malrotation of colon, Meckel diverticulum, omphalocele, pyloric stenosis |
| Renal | Double ureter, ectopic kidney, horseshoe defect, hydronephrosis, polycystic kidney |
| Musculoskeletal | Dislocated hip, radial aplasia/hypoplasia, short neck |
| Ophthalmology | Cataract, coloboma, corneal opacities |

*Source: Cereda and Carey[2] and Pont et al.[8]*

that may result in prolonged hospitalizations, and historical consensus has been that trisomy 18 is lethal.[6] Originally, even resuscitation was not indicated for trisomy 18, but the most recent edition of the *Textbook of Neonatal Resuscitation*, the American Heart Association, and the American Academy of Pediatrics removed trisomy 18 from the list of diagnoses for which it is considered ethical to not initiate resuscitation at birth.[12] Care options for trisomy 18 have become controversial,[6] however, because advances in medical and surgical management have created ways to address the known cardiac, gastrointestinal, and other anomalies (summarized in Table 2) that contribute to the short life expectancy associated with trisomy 18.

In cases of trisomy 18, decisions of whether to limit medical interventions rely on an assessment of many factors that must be considered from both the families' and the health care providers' perspectives. An appropriate question to consider would be "how much 'better' the infant's prognosis would be in terms of quality and quantity of life with an operative approach: might the infant live an additional 6 months? A year? More?" Issues of QOL, patient and family suffering, and appropriate resource allocation are uppermost in these decisions.[11] Other factors may include clinical considerations such as potential improvements in QOL or amount of required hospitalizations and/or surgeries; the ability of the parents to understand and interpret medical information; parents' unique goals for their children and their desire of whether to extend life at all costs; the parents' ability to care for a child with trisomy 18 if she/he survives; siblings and other family members; issues such as home resources, both financial and emotional; perception and amount of suffering the infant would endure from multiple surgeries; and religious and cultural beliefs and traditions.[11]

It is essential for the health care team to take into account all of these factors when considering care options for infants with trisomy 18. Disease severity may also be a factor in determining care options. The following questions serve as a guideline for thinking through options:

> Will the infant suffer when undergoing these interventions? If placed on ventilator support, will weaning occur? How many hospitalizations will be necessary? Should the treatments escalate at each point of organ dysfunction? Is this in the infant's best interest? How will this affect the family? Where will the family have to live? Will parents be able to work or perform normal daily activities? How many surgeries will be necessary? How much equipment will be needed at home? How will they pay for surgeries, durable equipment, and home care? What will the effect be on other children in the family? Will all the decisions have the ability to be revisited? Who will care for the child/adult when the parents are too old to do so? What will happen when the parents die?[13]

In the case described above, both the parents and members of the health care team struggled with how many interventions were appropriate for Monica and how many more options should be pursued as part of her care. The nurse's role in this instance is to advocate for both the infant and the family and to provide them with education and support as they weigh the available options. The questions listed here may be helpful as a springboard for conversations about care options. Perhaps, the most ethically laden question that serves as the crux of deciding whether to limit options for care for infants with trisomy 18 is "Because we can, does this mean we should?"[13]

## Who Makes Decisions When Options for Care Are Considered Futile?

Trisomy 18 was once considered a lethal condition, and resuscitation or surgical interventions for infants with this condition were considered futile and not in the infants' best interest. However, advances in medical technology have promulgated options to prolong life, albeit with pros and cons. The question remains, can avoiding care that is considered "futile" or not in the best interest of the infant be reconciled with parental wishes to provide ongoing treatment? The concept of futility related to options for medical treatment remains complex. Ongoing biomedical advances continue to expand the scope of what is physically possible, but that does not mean that such interventions always meet a family's overall goals regarding QOL. Questions for families and health care providers to consider when weighing options need to incorporate the following: (1) Will the intervention cause long-term suffering? (2) How long will the infant need to be hospitalized with each intervention? (3) Will the intervention change how care is delivered at home? (4) Are decisions being made reversible?

Because medical options for an infant diagnosed with trisomy 18 have changed vastly over the past 20 years, it is important when speaking with parents to avoid the terms *futile* and *lethal diagnosis*.[13] The concept of futility is not only emotionally but also intellectually charged. Physicians and state legislators have attempted to come to consensus as to how to best define medical futility. There is currently no definition that has been accepted by all states for futility; however, health care providers should still address this topic with families.[14] Cases of "absolute futility" are rare, and given the dynamics of any case, arguing that a procedure or intervention should not be done based solely on the ethical concept of futility would most likely alienate the family. Instead, conversations should focus on whether an intervention can accomplish desired goals. "An act is considered futile if its goals are not achievable or its degree of success is empirically implausible."[15]

Given this definition, treatments may be futile for one family and not another, given differing goals of care. For example, a family may choose an intervention to improve their infant's QOL at home by opting for an NGT or GT early on to avoid the risk of aspiration with oral feeds.[16] Another family, however, may choose not to have an NGT or GT placed and to attempt to feed their infant by mouth for as long as possible. However, challenges can occur if a family chooses an intervention with the hopes that a "miracle" will occur and reverse the current condition. Sarah and Sam struggled with each hospitalization and intervention Monica had to endure. They were cognizant of the differing viewpoints and attitudes on how assertive to be regarding treatments. Although, initially, they declined to speak with other parents in the same situation, they did a fair amount of investigating on the Internet. They made their decision based on their desire to give their daughter the best chance of having a good QOL, and for them, that meant minimizing Monica's admissions for feeding intolerance.

For health care providers, the decision to offer therapy that is deemed needless and/or unnecessary goes against the ethical principle of nonmaleficence, which states that providers have a responsibility to protect patients from intentional harm. In this case, the pertinent issue for everyone involved was to carefully determine what would be least harmful for Monica: frequent admissions or the potential to minimize hospitalizations with 1 surgical procedure. Undue pain and suffering without any benefit to the patient cannot be justified.[6] The focus instead should be on how to resolve differences when families and providers disagree on what is futile.[7] Together, parents and providers need to discuss the potential benefits and burdens of any intervention. In the case of Monica, the family's desire whether to pursue interventions was controversial.

## What Principles Guide Decisions About Care?

The American Medical Association asks that health care providers use the following factors when considering whether to treat a newborn with a serious illness: the likelihood that the intervention will succeed, the risks involved with treatment and nontreatment, the degree the treatment will extend life if successful, the pain and discomfort associated with the therapy, and finally, the QOL of the infant with and without the intervention.[17] Health care providers frequently struggle with offering surgical interventions when the diagnosis is associated with a very poor prognosis, in part because there is a belief that the intervention (surgical or medical) would provide no benefit and no hope for improvement.

When the prenatal diagnosis of trisomy 18 is made, parents are usually offered the following possibilities: termination during the first trimester, carry full-term to continue a palliative approach after birth, or provide aggressive resuscitation and interventions including surgical repair of any structural anomalies.[18] Over the past several years, physicians' positions have changed, where many neonatologists state they would be willing to initiate resuscitation based on maternal preference and the appearance of the infant in the delivery room.[19] A retrospective study of hospitalized patients ages 0 to 20 years with the diagnosis of trisomy 13 and 18 revealed that these children are receiving medical and surgical care in the hospital in part because they are living longer.[4] Health care providers need to be prepared to balance an overly negative picture of "poor prognoses" with the sometimes overly positive information given on some Web sites.[1] Even with the best of treatment, many children born with trisomy 18 will die within the first year of life.

## What Options Are Available to Nurses When Nurses and Family Members Do Not Agree About Suffering?

It is essential for nurses, who may struggle personally when they believe a patient is suffering, to recognize that answers to the ethical questions posed above are not "black and white" but rather often fall in the category of "gray." Ethical issues are multifactorial, and there are no right or wrong answers as to what should be done in many instances. Suffering can be personally defined for families, especially in the case of infants, who are unable to speak for themselves. Nurses, however, should speak with other team members when they feel conflicted about the amount of suffering that an infant endures. Resources including hospital palliative care teams and ethics committee consultations are available to help nurses think about these weighty topics.

## OUTCOME: MANAGING AND RESOLVING BIOETHICAL DILEMMAS

Did the nurses feel that the ethical issues had been resolved? Could they have been prevented? Rarely can we prevent these dilemmas from occurring entirely. In this case, Monica's parents were once focused solely on palliative care then transitioned to a more life-prolonging approach as she lived and became an integral part of their family. They had access to palliative care teams during pregnancy and throughout Monica's course, and although their views about which medical interventions were the most appropriate for Monica changed, they continued to keep her QOL at the forefront. In this case, nurses felt that their ethical dilemmas were resolved in that their voices were heard and the palliative care team and others talked with them about their struggles and acknowledged the difficulties of caring for seriously ill children and their families. Monica's parents continue to care for their daughter at home. Because of her innate fragility, she continues to require frequent hospitalizations and her parents continue to meet with the palliative care team in an effort to make decisions about what interventions will give Monica the best QOL possible.

## LESSONS LEARNED

The issues are not always clearly delineated and are different for every family. The choices that families make regarding medical decisions for their children with serious illness may change over time. There needs to be ongoing discussions with both the family and care team to ensure that the focus remains on the best interests of the child. Nurses caring for these children need to feel free to talk about their concerns and be supported in working through the struggles of providing this care.

## CONCLUSION

Because of advances in medical and surgical technology, trisomy 18, once considered a lethal disease, now presents families and providers with options to consider when thinking about the best way to proceed with care for these infants. Given the differing outcomes that exist for infants born with trisomy 18, several questions are raised that carry complex ethical implications, as described above. Nurses caring for these infants may find themselves thinking about these questions as they struggle with the best way to provide care for these patients and families while also feeling confident that they are doing what is in the infants' best interest. For this reason, it is essential that nurses and other health care team members identify the ethical dilemmas they face when caring for infants like Monica, as well as her parents, and use the resources available to them to address these challenges as they arise.

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