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Family-Centered Care of the Surgical Neonate

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When infants in the Neonatal Intensive Care Unit (NICU) need surgery the whole family experiences a crisis. Supporting the family, providing important information and determining their level of understanding are all important roles of the NICU nurse. The information behavior of parents is changing in the NICU as information is available through the internet but parents still look to the healthcare team first to answer their questions. Information needs change as the infant progresses through different stages along the illness trajectory (i.e. pre-operative, intra-operative, post-operative and post-discharge). This article will describe the information of needs of parents along the trajectory of surgical care and how nurses play a critical role for parents along the illness trajectory. Nursing actions vary along the pre-operative, post-operative and preparation for discharge continuum (see Table 1). However, supporting families is a constant through all of these stages.

Family-centered care (FCC) is organized around a belief that outcomes are best when families play an active role to provide emotional, social and developmental support to their child. (1) Principles of FCC include respect, honoring diversity, supporting parents' choice, and tailoring practices to individual family's needs. Communication between parents and health care professionals (HCPs) needs to be open, unbiased and honest. When care is family-centered, families feel supported and that their perspective is an important part of achieving the best outcome for their child at all levels of care so that they become empowered to discover their own strengths in the process.(2) Surgical care of the infant and their family requires constant information-sharing between HCPs and families.

Supporting parent's information needs

Research on parent's information seeking behavior in the NICU is lacking, although many authors acknowledge that parents get their information from many sources. Parents use many information channels including HCPs, written materials, peers, social media, electronic sources and audiovisual materials.(3?) Parents' information needs and their readiness to learn change over the course of their infant's hospitalization.(4?) They may need reinforcement of teaching until they fully grasp the information, sometimes many

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times. It is important to keep a record of teaching provided to parents and to accommodate their learning styles. To do this, HCPs need to ask parents about their learning needs and find the best ways to support those needs.

Although much of the literature describes HCPs as a primary source of information for parents, parents also provide information to the healthcare team that should not be ignored. FCC facilitates collaboration with parents as important information sources and competent decision-makers. Parents assimilate information from multiple providers over time and become the expert on their infants' behavior, response to treatment and past treatments and their effects. This can be especially true when the infant has been cared for in multiple settings (e.g. was born in one hospital, transferred to another, went to pediatric intensive care unit (PICU) and then transferred to NICU). In this case, it is especially important for parents to be empowered to share their experience along the illness trajectory as they are their child's best advocate.(1)

Nurses should expect parents will seek information from friends and family. It is necessary and useful to ask parents, "What have you heard about this disease or surgery from others? What questions do you have now that you have talked with the surgeon, your friends, etc.?" Help parents to organize information from multiple providers by encouraging them to journal. Facilitate open communication by mounting whiteboards to keep track of treatments, tests, feeding and activity orders near the infant's bedside. Provide a predictable time when parents can be routinely updated. Encourage them to participate in daily rounds when their baby's care is discussed and at change of shift if the unit uses bedside shift report.

Before birth

The type of information parents need varies across their infant's illness trajectory just as their readiness for new information and ability to learn new skills changes (3). Routine ultrasound screenings and assessment of fetal well being may detect surgical anomalies so that parents and the medical team can treat the infant most appropriately at birth. Prior to birth, if surgery is expected, NICU staff can meet with the family and provide anticipatory guidance about the potential for surgery, giving parents resource materials about the infant's condition. Neonatologists and neonatal nurse practitioners can discuss treatment options and determine family preferences. If transport for surgery is expected, the best method of transport is while the baby is still in utero. That way, mother and baby are kept together after birth as well.

Pre-operative acute phase

During an infant's acute phase, nursing can support the family by maintaining infant-family contact, providing culturally sensitive care, orienting the family to the NICU environment, and creating opportunities for two-way communication about the infant's condition. It is important to address parents' concerns and observations, and support the initiation and maintenance of the mother's milk supply.(5) When the infant is critically ill, parents may want to have the baby baptized by their priest or pastor. Honoring parent's spiritual needs will make them feel supported and the pastoral care department of many hospitals is available to support parents' spiritual needs. If transport is necessary after birth, the nurse is an important source of emotional support and information about the transport process and what to expect once they arrive at the receiving hospital. When possible, allow parents to speak with receiving neonatologist or transport team before transport.

A surgical consultation will be necessary and when the surgeon meets with the family, their privacy, comfort and decision-making needs should be considered. The surgeon will share

information with parents about the diagnosis, how it will be fixed, where the patient will go after surgery (e.g. PICU), NICU, etc.) and what the risks and benefits of surgery are for the infant. Often, parents may have questions after the surgeon leaves or have trouble remembering what they said. Nurses can encourage parents to keep track of questions that can wait until later and help get their urgent questions answered.

Post-operative

Post-operatively, the infant may still be on the ventilator and have much unfamiliar equipment at the bedside. At this stage, nurses can do their best to support parents and help them manage their stress. Keeping the infant comfortable and developmentally supported while explaining the procedures and treatments to parents are important roles of the nurse. They can encourage parents to maintain contact with their infant, explain the purpose for the equipment and provide guidance for how the post-operative course usually goes. Once the infant is post-operative and starting to improve, nurses encourage parents to participate more in their infant's care, educate parents to monitor and respond to their child's cues, provide anticipatory guidance for recovery, and work with parents to celebrate improvements and milestones.(5)

Discharge Planning

When preparing for the transition to home, parents should be given opportunities to practice care that will need to be continued after discharge, helping them to establish a "medical home" for the infant.(1,5) Parents need to be encouraged to actively participate in caring for their infant, learning how to feed, administer medications, recognize complications, and know when to call for help from medical personnel. At this stage, it may be helpful to make a referral for in-home visits by a public health nurse or for home health care if the infant needs more advanced care. Encouraging parents to repeat back the discharge instructions will help the nurse to know they understand their child's needs after discharge.

Along the illness trajectory, FCC can support families to participate in their child's surgical care and convalescence. The NICU course for the surgical infant can be uncertain, but health care professionals have the opportunity to empower parents. FCC approaches empower parents to promote decision-making and healing practices for both the infant and the family.

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Table 1**Nursing Care of the Surgical Neonate**

Pre-operative	Post-Operative	Discharge Planning
<ul style="list-style-type: none"> • Monitor vital signs • Ensure pre-operative labs are obtained, monitor for abnormal values • Assure 2 identification bands are on the baby • Stop feedings as ordered • Administer fluids, medications, treatments as ordered • Check that consent form for surgery and blood products is complete • Encourage parents to accompany baby when possible • Explain procedures and treatments to parents • Assure all records (including prenatal) accompany baby to surgery 	<ul style="list-style-type: none"> • Monitor vital signs • Maintain and support ventilation • Administer fluids, medications, treatments as prescribed • Maintain accurate recording of intake and output • Observe wounds for bleeding, report excess bleeding • Administer analgesics for pain • Use non-pharmacologic methods to improve comfort • Keep parents informed • Explain all procedures and treatments to parents • Start feedings when orders received from surgeon, encourage breastfeeding when possible 	<ul style="list-style-type: none"> • Encourage parents to feed their baby, provide daily care, administer medications and treatments • Make a plan with parents for follow-up with surgeon, neonatology, pediatrician, and lactation consultant as necessary • Educate parents as to when to call the Doctor, when to call 911, and who else can answer their questions • Consider calling parents 48–72 hours after discharge to answer questions and offer support • Make referral to community resources for in-home follow-up