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## Ethical aspects of care in the newborn surgical patient



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## ABSTRACT

This article places focus on three main subjects that are all related to the ethical aspects of care of newborns undergoing major surgical interventions. The first concerns the communication between the surgeon, as a representative of the treatment team, and the parents. The second is the way to handle new developments in neonatal surgery. The third issue covers several aspects of the ethical decision-making process with regard to forgoing life support in surgical neonates. These issues will be discussed on the basis of two clinical case reports.

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## Introduction

When discussing ethical aspects of the care for newborns, it would seem important to first define the actual meaning of medical ethics. Medical ethics can be seen as a system of moral principles, values, and judgments that apply to the practice of medicine in a cultural background. It is a discipline that gives the best possible reflection of different facets of the medical profession. The last decade has seen substantive shifts within medical ethics, mainly as a result of technological and scientific but also social developments. The field of medical ethics is now much more concerned with the meaningfulness of medical practice. Meaningful medical practice, we feel, is based on a dual concept. On the one hand, the good of medicine, with medical knowledge and technical progress determining the advisable course aimed at improving the patient's condition. On the other hand, the good of life, which means taking into account the current social views on quality of life.<sup>1</sup> Medical ethics covers many different subjects, therefore only some aspects can be highlighted.

This article places focus on three main subjects related to the ethical aspects of care of newborns undergoing major surgical interventions. The first concerns the communication between the surgeon, as a representative of the treatment team, and the parents. The second is the way to handle new developments in neonatal surgery. The third issue covers several aspects of the ethical decision-making process with regard to forgoing life support in surgical neonates.

All these issues have been subject of discussion and clinical research in our pediatric surgical department for many years.<sup>1–4</sup>

These issues will be discussed on the basis of two clinical case reports.

## Clinical case report 1

A male infant was born after a pregnancy of 38 weeks with a birth weight of 3860 g. Prenatal ultrasound revealed no structural anomalies except from a slight hydramnion. Due to inability to swallow saliva, choking on the first feeding, and failure to pass a naso-gastric tube into his stomach, he was admitted to the ICU of our level 3 children's hospital. The diagnosis of esophageal atresia with tracheoesophageal fistula was made, and no other associated anomalies (VACTERL) were detected.

The parents were very shocked by this unexpected postnatal course and had many questions about causes and consequences of this anatomical anomaly. Diagnosis, the necessary surgery, complications, and the expected postoperative course were discussed, and the parents gave consent to plan surgical correction. Through a minimal access thoracoscopic approach, the tracheoesophageal fistula was divided, and a tension-free anastomosis was constructed. The postoperative course was undisturbed except for a slight stricture of the anastomosis that responded well to several dilatations. The boy is now over 3 years old and participates in the interdisciplinary follow-up program for surgical newborns. He initially showed growth delay and psychosocial developmental delay, but at least the developmental delay has already been resolved to some extent.

Medical ethical considerations in response to this case report are as follows:

1. Pediatric surgeons have a special relationship with their surgical neonates; after all, the parents assume that they represent the best interest of their child.

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2. Minimal access surgery is a relative new innovative surgical technique introduced by individual surgeons and adopted in many pediatric surgical centers without evidence of its benefit.
3. Survival alone should no longer be the only parameter for successful treatment, but long-term follow-up of surgical neonates is equally important.

#### *Re 1. Communication between patient, parents, and the pediatric surgeon*

Medical specialists who treat children, like pediatricians and pediatric surgeons, have a special relationship with their patients. Taking into account the parents, there are at least three decision-makers. The child's role is largely defined by its age and decision-making abilities.<sup>5,6</sup> It goes without saying that the parents will act as surrogate decision-makers for newborn and other pre-verbal children. Decision-making belongs to their role as parents, and they will make their decisions based primarily on the best interest of the child. Since many anomalies are diagnosed prenatally nowadays, the initial conversations between parents and pediatric surgeon will often take place already before the child's birth. In this context, the surgeon, as member of the prenatal team, communicates with the parents about the diagnosis, the therapeutic options, possible complications, and short- and long-term outcome. Parents naturally tend to be greatly shocked when they hear that their unborn child has one or more serious birth defects. Often more than one conversation with the parents is necessary to let them understand the possible consequences. It is therefore of great importance that the parents are informed as clearly and consistently as possible based on large experience and without contradictory answers to their questions. This will help to reduce their stress in the final stage of the pregnancy.<sup>7</sup> In our pediatric surgical department, it is good practice that after a second consultation in the prenatal period the parents are invited to visit the ICU, where they are acquainted with the intensivists and nurses, so that they can familiarize themselves with the proceedings and the setting beforehand. Many parents gladly accept this invitation.

Let us now go back to the case of the above-mentioned boy, in which the diagnosis was not made until after birth. Consequently, the discussions with the parents about diagnosis and prognosis needed to take place after admission to the ICU. This can be challenging within the hectic environment of the ICU. Usually there is enough time to inform the parents adequately and to seek a well-considered informed consent before the surgical correction is scheduled. According to Nwomeh and Caniano,<sup>8</sup> the following four elements must be part of fully informed process: (a) the physician provides adequate information with which to make a decision to (b) a legal proxy who (c) indicates full understanding of the intervention, including the indications, risks, and possible alternatives and (d) voluntarily consents to the proposed intervention. Only in exceptional situations is asking informed consent not possible, for example, if immediate intervention is crucial because delay of the surgery could lead to serious harm to the child. After adequate information and recommendations about treatment, including potential benefits and risks, parents almost always give consent based primarily on the fact that they act in the best interest of their newborn. They often wonder about the cause of the anomaly; in most cases, however, we cannot answer this question satisfactorily. In a minority of diagnoses, genetic, environmental, or familial factors are identified and play an etiological role, but in most cases, the cause remains a mystery so far.

In an attempt to elucidate the causes of anomalies, a clinical geneticist evaluates all newborns with anatomical anomalies during the first admission. Whole genome arrays are performed

on the geneticist's recommendation. Blood from all patients and parents is collected after informed consent, for DNA-testing now or in the future. The information gained can be used to improve diagnostics and treatment of congenital anatomic anomalies.<sup>9</sup>

Parents will also like to know whether their child will survive, and if so, what quality of life can be expected. This question forces us to keep evaluating both our surgical and medical treatment modalities. With technical advancement progressing rapidly, we need to consider whether all these new modalities really contribute to optimal treatment of the child. Not only the evaluation of new surgical techniques is important but also long-term follow-up after surgery with attention to both physical and psychosocial functioning is equally important.<sup>10,11</sup> So, what are important ethical issues in relation to well-considered treatment?

#### *Re 2. Innovation in pediatric surgery*

Over the decades, much progress has been made in the technical possibilities of pediatric surgery, pediatric anesthesiology, and pediatric intensive care. Progress can be distinguished into improvement and innovation. Improvement is enhancing an already existing and often widely used technique. For example, using adapted surgical instruments or suture materials is mostly low-risk improvements, and these hardly have ethical implications. Innovation, on the other hand, is the introduction of something completely new, such as minimal access surgical techniques or new surgical devices. The goal of innovation is to solve a clinical problem in a manner that provides direct benefit to an individual patient or group of patients with a specific condition.<sup>12</sup>

In the case of the boy described above, repair of the esophageal atresia was through minimal access surgery by a thoracoscopic approach. This new technique has potential advantages: less postoperative pain and less risk to develop scoliosis at a later age. These benefits are less obvious regarding leakage and stenosis of the anastomosis.

Quite a few traditional open surgical techniques have been replaced by minimal access techniques as the preferred surgical approach for many surgical diseases. These approaches were introduced in medical literature and at scientific meetings by individual surgeons, usually from single institutions, by reporting their experience, the benefits, complications, and only seldom the learning curve. Subsequently, other surgeons adopted these techniques with professional enthusiasm.

From an ethical point of view, an innovative treatment should at least be defined in a clinical research protocol, and later in a randomized clinical trial.

"No surgical innovation without evaluation" is the title and main topic of a study by McCulloch et al.<sup>13</sup> McCulloch and colleagues propose recommendations for the assessment of surgery based on a five-stage description of the surgical development process. The first phase is the *Idea* (proof of concept) and sometimes needs ethical approval. Then, this phase must be followed by the phases of *development*, *exploration* (learning), and *assessment*. For these three phases, medical ethical approval is also required. The final phase is *long-term outcome*, for which ethical approval is not needed.<sup>13</sup>

In surgical disciplines, unlike the more contemplative medical professions, innovative surgical techniques are often introduced without evidence from (randomized) clinical trials. Yet these trials are considered as the "gold standard" in evaluating new therapeutic interventions. A study of Moss et al.<sup>14</sup> showed that randomized clinical trials constitute 0.17% of all the pediatric surgical literature and that only one-third were related to surgical intervention. Caniano and Ells<sup>15</sup> give several reasons for adopting operations without a (prospective) trial setting. The most relevant reasons are as follows: (a) suitable animal models may be lacking

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