The Child Surgeon:

Pediatric Surgery and the Endeavor to Cure Children in the OR

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Foreword

By Mike Chen

Performing surgery on a child is a complicated task. For the longest time, and while surgery on adults was already celebrating unprecedented success, surgery in children remained on the sidelines. Even during most of the twentieth century, babies born prematurely or with congenital malformations typically died. Following surgery, keeping them alive was difficult. Respirators for babies had not been invented, nor had neonatal intensive care units. The same was true for artificial nutrition. Without artificial nutrition, these smallest of patients often ended up starving to death.

Much changed in the middle of the twentieth century. A few surgeons became interested in extending to babies the tremendous success surgery had seen in adult patients. Breathing machines were adjusted so that babies could be ventilated artificially, and neonatal intensive care units sprang up in every major city. With the birth of neonatology, more and more surgeons used this new environment to perform surgery on smaller and smaller babies with congenital malformations. When artificial nutrition was invented in the late 1960s, further accomplishments burgeoned. The specialty of pediatric surgery grew and today counts amongst all medical specialties as one with the most successful cure rates.

I have been a pediatric surgeon for twenty-five years and have witnessed and lived through some of these changes. I spent the first half of my career learning the craft of pediatric surgery, and since then have focused on teaching future generations of pediatric surgeons. In the early 2000s, I built a pediatric surgery fellowship program in Gainesville, Florida. Later I was recruited to lead one of the busiest pediatric surgery programs in the USA in Birmingham, Alabama. In that setting, I first met Michael, who was one of my fellows in 2014.

Michael's career path has been unique from the beginning. He was born in Germany but grew up partially in the United States. He received his medical training from Ludwig-Maximilians-University in Munich, Germany, Harvard Medical School in Boston, USA, and Miguel-Hernández-University in Elche, Spain. At the latter university, he met his wife María, with whom he has shared an inseparable bond for seventeen years. Together they have two daughters, who are, even more than surgery, Michael's world.

After graduating medical school, he completed a surgical internship at the University of Texas in Houston and a pediatric surgery residency at the Dr. von Hauner Children's Hospital in Munich, Germany. He then came to train in pediatric surgery with us at the Children's Hospital of Alabama in Birmingham. When he finished here, he moved on to Emory University in Atlanta, Georgia, to pursue his lifelong dream of becoming a liver transplant surgeon.

In Georgia, he wrote the first version of this book. How he managed to write a book while training as a transplant surgeon, undoubtedly one of the physically hardest and most time-consuming fellowships in US surgical training, is incomprehensible. I once asked him, and he admits that he wrote the first version mostly at night and in between organ transplants. Out of exhaustion and unable to sit up, he would lie on his back, typing each of the 125,000 words with his thumbs on a tablet. Because I have known Michael for several years, I can easily imagine this recollection being true.

Once completed, he submitted his manuscript to the Department of Faculty Development and Excellence at Emory University and was awarded their young author book-writing grant. After several edits and input from friends and colleagues, he is now publishing the first edition.

When he initially arrived in Birmingham, he was eager and hungry for surgical training. He had been in a residency for a few years before coming to the USA, and although his touch and judgment was unfinished, he obviously had talent. He was clearly behind his peers in our program since they traditionally have substantial hands-on experience early in training. The way he responded to this circumstance impressed me then and has made a lasting mark on me. Instead of letting himself down, he saw an opportunity. He identified his weaknesses and challenged himself to improve. Through hard work and tenacity, he caught up with his peers and became an outstanding surgeon–one who has empathy for the patients and has the technical excellence and thoughtful clinical judgment to provide exemplary care. To see someone like Michael grow and continuously mature over the years to become an astute surgeon is one of the things I have come to love most as a teacher.

One good reason to read his book is the fact that it was written by a young surgeon straight out of training. Michael has an honest and fresh perspective on what lies ahead, not only in medicine and surgery but also in life. It is always more challenging and riskier to write about what is next to come. Michael's book is insightful and sensitive, yet compelling and vigorous. It clearly delivers on the task.

The book touches on all facets of what is vital in performing surgery on a child. It gives the crucial historical background and puts into perspective the tremendous medical opportunities that have become possible. Pediatric surgery as a medical specialty is at the peak of its development, and we can now treat conditions that were formerly non-survivable. The book covers a broad range of topics. Cancer in children is as much discussed as organ transplantation, congenital malformations, prematurity, life-and-death decisions, pediatric surgery in a global context, and what it can mean for parents to live with a disabled child. By covering these topics in simple, easy-to-read language, Michael has made this book accessible to everyone. Also, what makes this book a positive and helpful read is the fact that when encountering shortcomings in our profession, he never accuses, but instead explains. Thereby, he leaves room so that the reader may make up their own mind about the challenging issues discussed.

The book additionally takes into account some of Michael's personal experience while training to become a surgeon. Many of them are representative of what young people go through these days when trying to move forward on an individual path—on the job, at home, and in life in general. His story will be much appreciated, especially by a young person heading for a career in health care.

Many books have been written about the craft of surgery in children. Most, if not all, are medical textbooks directed to the colleagues in the field and around the world. This book is written for the lay reader and is, therefore, a true first. It traces the birth, growth, and future of our specialty in plain words and is accessible for everyone interested.

One of the most exciting features of this book is its perspectives about the past, the current, and speculations about the future of pediatric surgical care. Additionally, it delves into human nature and our hidden bias that flaws our perception of the truth. Michael has made the unconscious cognitive bias of humans a critical discussion that I valued a great deal in my review of this work.

This insight has tremendous importance for medicine, but specifically for the care of children. The vulnerability and innocence of a child call for even greater responsibility and provide yet another good reason to engage in reading this book. After all, parents and doctors decide what medical or surgical treatment to give to a child—often with lifelong consequences. We owe it to the children and the future of our society that we do the best we can to do it right.

Mike Chen, MD
Birmingham, Alabama, 2019

Preface

Isn't it strange
That princes and kings,
And clowns that caper
In sawdust rings,
And common people
Like you and me
Are builders for eternity?
Each is given a bag of tools,
A shapeless mass,
A book of rules;
And each must make–
Ere life is flown–
A stumbling block
Or a steppingstone.
R. L. Sharpe

Throughout all of history, children held crucial roles in supporting the family and their community. Not only did children contribute by working in the fields and during the hunt, their bonds with other families meant the continuity of the family bloodline and with it the lands, goods, power, and perhaps even spiritual values that stood behind them.

In modern societies, the economic success of a family is less likely to depend on the number of healthy offspring. Contemporary parents increasingly see their children as personal fulfillment instead of means to a secure future, a concept that developed around the time of the Renaissance. Over the centuries that followed, and despite succeeding brutal exploitation of children as cheap labor force during the time of the industrialization, this idea of the “sanctity of the child” became more and more engraved in the current perception of human offspring.

Today, in the Western world, children are generally well protected and educated by their parents and society. The motivation behind this nourishment reflects not only the individual love for the child, but also what children have meant and will always mean for society: once grown, they fill universities, operate harbors, make up the workforce of security and political agencies, compose for the concert halls of the symphony orchestras, care for the frail in the community, and protect peace in the world. Children may no longer be critical for the survival of the individual family, but they are for society as a whole. Investing time, money, and empathy in offspring then means what it has always meant: to invest in the future of society. We love children for who they are, and we value them for who they will become.

With this viewpoint in mind, illness in a child is a tragedy on multiple levels. When children fall ill, parents, caregivers, family, friends, and members of the community suffer. The misery of their offspring is inherently upsetting to adults. Given the vital role that children carry for the progression of a mature society, this agony is anything but altruistic. A sick child threatens not only the existence of the affected child but, in truth, jeopardizes the integrity of the community.

Pediatric surgeons belong to a group of doctors who exclusively focus on surgery in children. Their specialty is relatively new and arose only in the last fifty years. Albeit a young medical specialty, pediatric surgery has become one of the most prestigious and highly specialized fields in medicine. Pediatric surgeons now perform corrections of birth defects that were non-survivable only years ago, and their success rates in treating cancer outshine that of any cancer diagnosis in an adult. Clearly, treating children is a rapidly growing and transformative field and is also an enormously lucrative one. About fifteen billion dollars currently are being spent to build additional children's hospitals in the United States alone, and these facilities will bring more and highly specialized pediatric and pediatric surgical care into the corresponding communities.

Despite these efforts, children who require surgery continue to suffer. The reasons are multifactorial: hospitals distribute their resources unwisely, policymakers fail to centralize care of children with rare diseases, and research performed in pediatric surgery generates unsatisfactory evidence. With increasing pressure from a broken health care system, progress has slowed down. Each innovation comes at an astronomical cost but reaches only a few children while sparing thousands of others. With the lives of our children at stake, the fast-growing field needs self-examination and self-reflection. Unfortunately, they are sparse attributes in the health care discussions of today.

The Child Surgeon recounts the story of the birth, growth, and future of surgery for babies and children. In tracing the history of the success story of pediatric surgery, the book discusses both the challenges and opportunities that lie ahead. This book is for everyone: nurses, physicians, residents, fellows, medical students, patients, parents, grandparents, therapists, hospital administrators, legislators, and anyone else interested in the care of children. The reason I wrote it is simple. Until now, it was a book that I felt was missing. Many misconceptions exist about caring for a severely ill child—whether on the part of a surgeon, a pediatrician, or another physician, nurse, parent, or caregiver. Pediatric surgery is not merely the concern of a few highly specialized surgeons and a handful of affected parents. Because caring for offspring is a direct reflection of societal values, it resonates with all of us. Rarely are these concerns condensed, discussed, and analyzed from this angle, let alone in one place. The book may make its most important contribution by creating awareness about the challenges pediatric surgeons and their patients and families face today and by simultaneously engaging in the discussion about how to make improvements. Although answers are not always obvious, perhaps the book can help to bring together parents, surgeons, policymakers, the community, hospital administrators and pediatric patients and contribute to the ongoing and much-needed public dialogue about improving the health of children.

Without a doubt, my view on pediatric surgery is biased. My work has brought me, along with my wife and family, more happiness and joy than anything else I have experienced in life. I am a person deeply committed to my profession. Throughout the text, I could not avoid to express some of the reasons that led me to become a pediatric surgeon. At all times, I tried to use my personal story only with the intention to allow the bigger picture to unfold.

Many people, including parents, patients, teachers, hospital administrators, friends, my family, and others, have profoundly influenced my perspective on my specialty. To them, I am forever thankful. The book recounts key patients' and family's stories, and I am aware that their views on what occurred might not always coincide with mine. The stories recorded here are the product of my memory. In all cases in which I tell the stories of my patients, I have tried to protect their privacy. Any similarities that overlap with true identities are pure coincidence.

The book opens with a case of a child that I cared for when I was a young surgical resident, and that ended in a disaster. The book closes with the understanding that most children in the world continue to suffer and die from the same surgical diseases from which my specialty was born. Both these realities raise questions that I have pondered over the course of my training to become a pediatric surgeon. In truth, this book evolved from my struggle to answer them.

In between these extremes, the book considers the specialty of pediatric surgery, including its historical precursors, development, and current status, both in the Western world and around the globe. Early on, the book describes common surgical diseases that affect children. Even though these accounts are rather descriptive and less analytical, they are important. Unless affected themselves, most people in the general population know little of what kind of work pediatric surgeons do nor what challenges they face. Some diseases cause an unspeakable magnitude of suffering. My specialty intends to alleviate that suffering.

Becoming a pediatric surgeon takes roughly fifteen years of structured medical and surgical training. The intense and prolonged training of a pediatric surgeon reflects what is at stake when surgery is performed on the most vulnerable of all patients. A pediatric surgeon's training comes with additional, unique challenges. Young individuals start their training as boys and girls fresh out of high school or college and finish as full-fledged surgeons in their mid or late 30s. The challenge that comes with training for such a long period of time has implications not only for the surgeon but also for the patients. The examples are many, but one of the hardest lessons a surgeon must learn is to accept personal failure and that of the health care system.

Failure in surgery is called a complication. In a field in which the margin of error is amongst the smallest in medicine, serious harm and death from a medical error or a complication is a constant companion. An entire chapter will address this important subject. The discussion of complications in pediatric surgery is imperative because the public often misunderstands what a complication means in the medical sense. This misunderstanding has lead surgeons and hospitals to avoid disclosing complications to their patients and the public. A cultural shift in how surgeons and hospital administrators approach complications and medical errors towards a more open-minded attitude is underway. The result can be a valuable dialogue between surgeons and parents to avoid frustrations on both ends of the knife.

The following chapters of the book explore how the health care system integrates pediatric surgical care and how the community perceives it. Many health care systems in the world take distinctive approaches to provide pediatric surgical care. No system is perfect, but learning from one another is valuable and worthwhile. Over a total period of sixteen consecutive years, I have trained in two surgical specialties in five different countries on three different continents. During this time, I trained at some of the most prestigious hospitals in the world, such as Harvard's Massachusetts General Hospital in Boston, and in some of the most deprived areas in the world, such as the Jimma University Hospital in Ethiopia. My training abroad and the perspectives I gained by these extremes has helped me consider the different features of each health care system and perhaps was one of the most enchanting facets of the education I was privileged to receive. In reflecting on this experience, I hope to raise helpful questions about nurturing the logistical progress of our health care systems.

No matter where in the world children undergo surgery, some difficulties are shared across borders. Surprisingly, little scientific evidence exists for the therapies pediatric surgeons apply. In his book *The Laws of Medicine*, Siddhartha Mukherjee, author, scientist, and winner of 2011 Pulitzer Prize, correctly states: "Most of our models of illness are hybrid models; past knowledge is mishmashed with present knowledge. These hybrid models produce the illusion of a systematic understanding of a disease—but the understanding is, in fact, incomplete.” What is true for most of medicine is true for pediatric surgery. Health professionals carry out many therapies simply because they worked reasonably well in the past. We act based on experience and belief instead of evidence and truth. Pediatric surgeons, compared to other specialists in medicine, have had difficulties comparing their therapies to alternative treatment options. Many of the diseases in the field of pediatric surgery are exceedingly rare. Also, the few rare cases that do exist are spread out over many different hospitals, making it difficult for individual centers to obtain sufficient expertise in specific types of surgery. For those reasons, in some areas of pediatric surgery, recently progress has been slow.

Perhaps the most significant exception to this observation is how pediatric surgeons together with pediatric oncologists treat childhood cancer. Over the last fifty years, tremendous advances have occurred in the field of pediatric cancer care. These advancements have led to a much-improved survival rate for children with cancer, as long as they live in an area of the world in which expensive cancer treatments are available. The corresponding chapters describe not only how these advances became possible but also what the limits of current therapies may mean for the future.

The book also includes a discussion of solid organ transplantation in children, which has seen tremendous progress over the last decades. To share an organ with a loved one or a total stranger, and thereby spare a child’s life, is a beautiful and selfless act. This gesture indicates a mature and compassionate society, engaged in a higher goal than merely the perpetuation of individuals. Unfortunately, solid organ transplantation today is far from perfect. Organ shortage and rejection remain a substantial limitation. My discussion of this topic, therefore, goes beyond conventional organ transplantation. I explore the possibility of bioengineering tissues and whole organs and how these technologies could shape organ transplantation and other areas of medicine in the future.

Whether a child requires cancer surgery, organ transplantation, or some other invasive therapy, pediatric surgeons, together with the parents, face enormously challenging decisions, many of which involve life and death. Most often, no right or wrong answer is apparent. In many scenarios, predicting individual outcomes is impossible. Ethical guidelines exist, and we work continually to improve and help with such decisions. When we cannot decide by using scientific evidence, we must inevitably decide with our hearts. Children in any given society have and always will have serious illnesses, including debilitating, chronic conditions that are painful for all involved. The daily struggles of such children and their parents are humbling, and they teach us all valuable lessons. The importance of integrating disabled children into our society is under-appreciated, and compassion in isolated cases is not enough.

The book closes with a perspective on pediatric surgery in global health. While surgeons provide sophisticated care for children in the Western world, the overwhelming majority of children in the world continue to suffer from the same maladies that once inspired doctors to give birth to what is now the specialty of pediatric surgery. In low- and middle-income countries, disability, illness, and premature death in children transitions into an adult workforce that is reduced both in quality and quantity and can cripple the development of these countries. The discussion of these economic and social components of disease in children puts into perspective an epic struggle and also an ethical one. Fortunately, solutions are possible, although they are not as easily applied as in other areas of medicine.

The timing of this book does not come arbitrarily. As I write these lines, I am finishing a sixteen-year-long training period as a pediatric and transplant surgeon. During these years, I spent almost every waking minute learning about the surgical care of children and reflecting on the issues involved. I have performed thousands of operations, mostly in children; I have transplanted hundreds of organs and perfected both my technique in the operating room and my clinical judgment on the wards. On good days, I come close to my full potential; I treat patients, listen, help out, alleviate, and in some cases, even cure. In short, I perform the duties expected of a doctor. Despite excellent training and best efforts, however, on other days, I inadvertently fail those around me—my teachers, my family, myself, and saddest of all, my patients. These experiences, too, shape this book.

During the many years of medical and surgical training, I learned two things. The first lesson is the realization—and I say this only with constructive intentions—that our health care system and the way we practice surgery in modern times remain imperfect. Evidently, surgery is more successful in alleviating suffering than it ever was. With ongoing medical progress, however, come new challenges. The biggest challenge in modern medicine certainly is, without any doubt, unconscious bias. In medicine, bias is defined as a distortion of the truth. Unconscious bias then refers to a systematic distortion of the truth that does not seem apparent, especially not to the patient but often not even to the doctor. Unconscious bias typically stems from specific prejudice and is based on emotions instead of facts. Understanding this insight is crucial. The scientific evidence of today is full of unconscious bias, which threatens the core principles of medical progress. Flawed studies, framed perception, faulty and incomplete evidence, absence of knowledge, as well as traditional, almost religious belief in unproven principles and all kinds of alternative medicine and therapies mislead physicians and patients alike and limit the ability to reduce suffering and make meaningful progress in the years to come. The bias we see in medicine today and how it impacts medical and surgical decision making will be a recurrent theme in this book—never to point fingers, but to create a realistic perception of the limitations and opportunities that lay ahead for our children. The point is that the bias found in modern medicine, and in pediatric surgery, is not only highly recurrent but follows predictable patterns. The good news is that understanding the underlying principles enables us to better manage, if not prevent, negative and harmful consequences.

Another important lesson I learned is that developing humility and mindfulness is a crucial component of evolving as a surgeon, a doctor, and a person. To be a capable surgeon, excellent training and exceptional skill certainly are necessary. Once the craft of surgery is mastered, however, humility and mindfulness make a good surgeon exceptional. By mindfulness, in this context, I mean the capability of a surgeon to step back and to reflect on the bigger picture. To acknowledge the awesomeness of our knowledge that we have gained in science over the last decades but to also accept its limitations. Perhaps one goal is to accept and learn how to outmaneuver the flaws and biases in modern medicine. A master surgeon never stops learning. Instead, life-long learning is what defines a master surgeon, and this attribute comes about only in humility.

In a broader sense, this vision applies not only to my specialty but also to society in general. As a society, we move forward only if we strive to learn about ourselves and from each other; this mindfulness is what makes a society mature. The way any society treats and cares for its offspring in disease and suffering is a critical reflection of this maturity, and because pediatric surgery has become a crucial part of this endeavor, the discussion brought forth in this book impacts not only those affected, but everyone.

Chapter 1

Santiago

There can be no keener revelation of a society's soul
than the way in which it treats its children.
Nelson Mandela

Every minute of every hour of every day for our entire lives, we must breathe. Under normal circumstances, oxygen carried in the air enters our body through the mouth and nose and then travels down the windpipe. The windpipe, at its lowest point, splits into two smaller pipes–the left main stem bronchus carries oxygen to the left lung, and the right main stem bronchus sends it to the right lung. From the lungs, the oxygen passes through a thin layer of specialized cells, the alveolar epithelium, and enters the bloodstream, where red blood cells transport it to the rest of the cells of the body. By this mechanism, oxygen reaches the cells of every organ—including muscle, brain, and bone marrow.

Not only do we need to breath in oxygen that is present in the air, but also must we exhale carbon dioxide that accumulates in the bloodstream. Carbon dioxide is one among many waste products that builds up in the human body when metabolism generates energy, such as when neuronal cells solve a mathematical equation or during a run in the park. The carbon dioxide then travels in the reverse order—from the cells of the body into the bloodstream, from the blood over the blood-air barrier of the lungs into the windpipe and out through our nose and mouth. Without this constant emission of carbon dioxide, humans would not survive even a few minutes. Fascinatingly, the plants and greens that make up the forests of the world are poled in precisely the opposite way. During photosynthesis, they breathe in carbon dioxide and release oxygen as their waste product—a setup that has permitted humans to live in perfect harmony and symbiosis with the natural environment.

Santiago could not breathe. He was born early into the world in Lisbon, Portugal, at only thirty-three weeks of gestation. The pregnancy had been uncomplicated until then, but when he was born prematurely, Santiago weighted only 1500 grams. More significantly, he was born with a rare congenital malformation, which inhibited him from breathing and thus from living. Santiago's right lung did not originate from the windpipe, as it should have; it originated from the esophagus. Hence, no air could be delivered to the right lung, only to the left lung, which was not enough to survive at such a young age. The lack of oxygen caused Santiago's breathing to be heavily labored, and without artificially ventilating him with a machine, he could not have survived. Also, because of the lack of air in the right lung, this lung was always in a collapsed state and formed a favorable, sealed environment for bacterial growth, which sooner or later would result in severe and recurrent infections. To make things worse, bacteria, naturally present in the esophagus, entered the lung and caused further bacterial overgrowth, infection, and damage. As if this were not enough, Santiago had a severe narrowing of his windpipe that inhibited the flow of air to his functional left lung. While such a narrowing of the windpipe may be fairly common, doctors know of only a handful of cases around the world with a combination of malformations similar to those they saw in Santiago.

The fragile child was initially treated in Lisbon. Shortly after birth, a plastic tube was inserted into his windpipe to facilitate breathing, which had to be carried out by a machine. At that stage, nobody knew why Santiago's breathing had been labored, and this measure was performed out of necessity: without such a breathing tube, Santiago would have quickly died. Then, the medical team performed a series of studies. First, a standard blood test was conducted to rule out infection or electrolyte or sugar imbalances—

all things that could have accounted for Santiago's poor condition. After all tests had come back inconclusive, more invasive and expensive tests were ordered. A CT scan of the chest showed what a chest x-ray had suggested—a wholly collapsed lung on the right that did not seem to participate in the gas exchange. On this same CT scan of the chest, however, the attentive radiologists were puzzled with another observation they made. None of them had ever seen anything like it before, but scrolling through the images on their computer screen, they clearly saw it. The right main bronchus, and with it the right lung, arose not from the windpipe itself but from the esophagus. Everyone immediately knew that this aberration in Santiago's anatomy was what made him so terribly ill.

To be sure of this unusual diagnosis, the physicians in Lisbon gave Santiago dye to swallow. As he drank it, they took several more x-rays and, on a computer screen, followed the dye from when it entered his mouth until it reached the stomach. Initially, this study was interpreted as normal, and the contrast material nicely delineated the inside of the esophagus and passed quickly though to the stomach. Importantly, no contrast material seemed to spill out of the esophagus. Again, the radiologists were very puzzled because the CT scan had suggested otherwise. If there was a connection between the esophagus and the right lung, then the swallowed dye should have spilled over into the lung.

At the very end of the study, however, and right before bringing the child back to the ward, Santiago suddenly coughed, gagged, and threw up a little. The radiologist, with a pure gut feeling, he later admitted, brought Santiago back on the examination table and took one more picture. What he saw astonished everyone. The entire right lung was filled with dye. They had confirmed the reason why Santiago had such great difficulty surviving. The right lung connected with the esophagus, and not with the windpipe, and the gagging had caused the contrast material to spill over from the esophagus into the right lung. His internal structure was but a small deviation from nature's perfect plan. Unfortunately for Santiago, this small peculiarity had dramatic consequences.

With a problem as complex as this, the physicians transferred the child to Seville, Spain for specialized care. Seville is a major referral center for congenital malformations of the windpipe, and most such cases of the southern Iberian Peninsula and Morocco are either transferred to Seville or to Madrid. In pediatric surgery, under ideal circumstances, referral centers are designated for specialized care of rare diseases. The transport of children like Santiago to specialized centers ensures that, despite the rarity of a condition, knowledge of how to diagnose and treat these children can accumulate and benefit succeeding cases. In Spain, one of the surgeons in charge of treating children born with malformations of the windpipe is Jose Antonio Matute Cadenas, gently called Josechu by the staff of the hospital and friends. Josechu, in his fifties at the time and a heavy smoker, is a nationally and internationally renowned specialist for malformations of the lungs and windpipe in children. At first glance, he resembles the old generation of surgeons: over-confident and invincible to criticism. Contrariwise, as I would later discover, his mind and touch in the operating room were among the most gentle and modern I have seen in my years.

After Santiago's transfer, it was clear that only a complex surgery could save his life. Arrangements were made, and Josechu would take the lead on the case. At the time of his operation, Santiago was only a few months old, but I felt equally immature and unfit for correcting what was making him so ill. I was a young resident at the beginning of my surgical training on an external rotation in Seville and merely an assistant to the lead surgeons in Santiago's operation. Nevertheless, as all doctors do, we see and treat some patients whom we remember for a lifetime. For me, Santiago is one of these patients. After all these years, still—as if it were yesterday—I can feel the emotions involved that day, and I can still smell the burned flesh and the dried blood and hear the voices of the people speaking during that particular operation.

On the day of the surgery, we first opened Santiago's chest through two separate incisions. Through one on the right side we detached the faulty connection of the lung to the esophagus. The other incision was through the middle, through which we opened the sternum and split it in half, which placed all the vital organs of the chest right under our nose: the lungs on either side, the heart in the middle, and behind it the esophagus and the windpipe.

As we had planned, the cardiac surgeon came in to help us place large plastic cannulas into the heart, which we then connected to the heart-lung machine. After cooling Santiago's little body down to about twenty-six degrees Celsius, we paralyzed the heart with a potassium-rich solution, which gave us access to the windpipe behind it. Because the exposure was not good enough, however, we had to go one step further. Not only did we stop Santiago's heart, but we also emptied out most of his blood volume into a specialized container, where it was temporarily stored. Then, we stopped the heart-lung machine, something surgeons call complete circulatory arrest. With this maneuver, there was little blood in Santiago's body, and circulation was entirely stopped. Hence, there was no bleeding that obscured our view. We now had full access to where we needed to work, and Josechu began the most critical part of the operation.

The technical expertise required to perform such delicate work is extraordinarily high. The sutures we used were barely thicker than a human hair and could be handled purposefully only with the help of magnifying loupes. Additional pressure stemmed from the fact that we were working against time. We all knew that we could permit ourselves just a few minutes of complete circulatory arrest before Santiago's brain would suffer permanent damage. With this weight on the team's shoulders, the tension in the room was palpable. As one of several assistants, I observed Josechu's every surgical move. I watched not only his hands but also the expression in his eyes and the tone of his voice. Concentrated, focused, determined, and dedicated, all at once, he made use of a repertoire of experience and skills acquired over decades of training. His hands moved quickly with a degree of precision I have rarely observed in a surgeon, and he wasted no movement. Frankly speaking, it was not an operation that he performed; it was a masterpiece of art. Until this day, I have no other words to describe his performance.

After Josechu had finished his part of the operation, we carefully returned Santiago's blood back into his body. We then warmed his body and restarted his heartbeat with a small electric shock. The residents and cardiovascular surgeons took out the big cannulas that led to the heart-lung machine and closed Santiago back up. Shortly after that, Santiago was transported to the pediatric intensive care unit. The operation had been a success. None of the anticipated technical complications had occurred, and Josechu shared the exhilarating news with Santiago's parents.

Fifty-two days after the operation, Santiago died. After he returned to the intensive care unit, he continued to have a long, frustrating, and ultimately unsuccessful fight against the condition that brought on our surgery. Even given the capacities of modern medicine and everyone's best intentions, one complication led to another. In the end, the many physicians, surgeons, neonatologists, pediatricians, radiologists, cardiologists, nephrologists, and intensivists had nothing more to offer. The nursing staff, the physical therapists, the clerks, all who spent countless hours attending to wounds, drains, feeding tubes, catheters, monitor alarms and, most importantly, the physical and emotional needs of Santiago's parents—all had lost something treasured. The parents lost even more. Their only offspring had died. Everyone involved lost what was so precious to us during that unfortunate day. We lost Santiago. We lost the life of a child.

Santiago's story is important because many lessons come to light from understanding it. Children die every day. Thousands of them deteriorate needlessly in a spiral of suffering and agony. Every few seconds, across the world, a child dies of malnutrition or diarrhea. Why so much fuss about this one child? Was it because he was one of ours, or because it was happening right in front of our eyes? Perhaps we felt emotionally connected because we were involved, or took it personally that disease scored a victory, from a scientific, academic, and professional perspective? Was our pride and integrity at stake?

All of these possibilities probably carry some truth, and the answers may differ for each individual involved. Even though we grieved with the parents, our perspective on the death of their child was much different than theirs. We as the physicians were distressed that after what was technically a sound operation, nonetheless, we had so little else to offer Santiago. We reviewed the case from beginning to end. We even published the case, analyzing our steps critically, and shared these thoughts with our peers across the world. We discovered that the standard guidelines set out for patients with conditions like Santiago's varied, and no single error or misjudgment or single act led to his death. Concerning the postoperative care, we noticed that many of the standard approaches that work well for other children in similar situations just did not hold up in Santiago’s case, despite all efforts to adapt the care to Santiago’s individual circumstances, many of which were new. This fact alone put Santiago in a difficult position from the start. Doctors, especially surgeons, perform well when treating the same disease or condition over and over again. In Santiago’s case, there was no repetition. Because this malformation was so rare, for everyone involved, this case was a first. We had done the best we could for this child, which, looking back, was one of the hardest realities to accept.

Oddly, what I find saddest in the death of Santiago is surprisingly also one of the certainties that gives me the most comfort and has motivated me to pursue a career as a pediatric surgeon. On the one hand, Santiago never once left the hospital. As a matter of fact, not counting a few trips across the hallway to the operating theater and down to the ground level to the CT scanner, he barely even left the intensive care unit. I find this thought incredibly sad. The happy parents never came home with their baby, welcomed by neighbors and friends. On the contrary, the parents came home exhausted, after a long day in the intensive care unit and after listening to the countless reiterations of the doctors’ medical talk, all while they saw no signs of progress. Every night they wondered if Santiago would still be alive the next morning when they returned to the hospital. They froze for brief instances each time the telephone rang; horrified it would be the physician calling to deliver the terrible news.

On the other hand, this does not mean that Santiago was not loved. As a matter of fact, I would argue that he was loved more not despite but for his illness, and he was treated in precisely that manner. His life was not unworthy of living. It was a life, unfortunately, cut far too short. I came to this realization for the first time in my career with Santiago’s death, and his case is essential to this story and this book.

On the day of his passing, we had taken Santiago back to the operating room. His last trip to the operative room was a desperate attempt to fix a gaping hole in his windpipe that resulted from infection and reduced blood supply to one of our most critical suture lines. This hole permitted air to gush out of the lung into the chest with no chance of maintaining enough air inside the lungs to survive. Our attempt was futile. Santiago died on the operating table, under our gloved but otherwise bare hands.

It was early in the evening. First, no one spoke. After a long silence, Josechu announced the time of death. Santiago's little body lay silently and motionless before us, still warm, almost as if he were sleeping. Alarms and monitors were shut off for good; tubes and drains were removed. We closed the skin, thereby covering up the wounds that had taken Santiago's life. I remember that what happened next surprised me. The nurses tended to Santiago as if he were still alive, groomed, and dressed him neatly and placed him in a beautiful little bed. One of the senior nurses pushed his crib into the recovery room, and all other patients were transferred out. The room light was dimmed, and Josechu himself lead the parents to their dead child.

Santiago's mother Ana was a young, beautiful woman in her late twenties. I had met her countless times before on rounds, and many times we sat down together to discuss the details of Santiago's care. I remember how impressed I was with the courage this young woman had possessed throughout the process of Santiago's illness. She was both knowledgeable and well-read on his condition, and she was sturdy and firm when she felt that she needed more information from the various medical teams involved with Santiago's care. She was aware of the risks involved from the beginning and from our many conversations I knew that she managed to incorporate these risks into a reasonable and realistic overall picture of Santiago's disease. She knew that despite our best endeavors to treat him, Santiago's death was a real possibility.

After Ana and her husband entered the dim and silent room, however, what came next was something I utterly and downright was unprepared for. Until this day, as I am writing these words more than ten years later, a cold shiver runs down my back when I remember the moments that followed. For some naïve reason—perhaps to protect myself—I had assumed that because Ana was so involved in the realities of her son's care, she would somehow be protected against the full emotional impact of the certainty of Santiago's death. How wrong I was. The moment Ana put her eyes on Santiago, she howled out a shriek so chill and heartbreaking that I thought the world came to an end, only to realize instantaneously that this was what was happening to Ana. We all stood back saddened and speechless. On and on, she cried out in tears, and each cry shot through my bones like a knife. We seated the parents next to Santiago's body, and with trembling knees, I took him out of his crib and placed him into the mother's arms. I only realized later that it was then that she held Santiago in her arms for the first time. A few more times Ana cried out in agony, then inaudibly wept away in bitter silence. The sounds of her misery were gut-wrenching, and for a lifetime, I cannot forget these sounds.

Listening to a mother moan over her dead child's body is the most painful experience I have had to endure as a pediatric surgeon. Unfortunately, throughout my training, I repeatedly had to live through similar situations. Although over time I have better prepared myself for this reality, the death of a child is never easy to bear. I wonder whether I will ever grow numb to the emotions that fill me during those heartbreaking moments. For my own sake (and for the sake of my patients) I hope I never will.

We all sat together for a little while, and then we left the parents alone to say their goodbyes. Later, Josechu would sit with them again past midnight, talking, caring, loving, and guiding their grief. In Germany, where I mostly grew up, showing emotion in such situations is not regarded as manly or professional. Be that as it may, seeing and hearing this mother moan for her dead child struck my heart to the core. I remember feeling shocked but thankful and alleviated because Josechu, who was a role model for every surgical trainee in the hospital, also felt emotional upheaval. I was moved to see how touched he was. Minutes before he had opened this baby's chest in less than ten seconds with the bare blade of a knife—stone-cold without the slightest wink. Now, he sincerely participated in the grieving for the lost child.

The fact that Santiago was so loved still comforts me. Seeing all the grief and love after Santiago's death made me realize that, yes, in pediatric surgery we do much for the children and their parents. We also, however, act not just for them, but also for ourselves, as if Santiago was our child. Doctors train for a decade to treat children just like Santiago in hospitals around the world. We bring in a team of highly trained specialists and perform an array of medical tests. We perform heart and liver transplants and spend tremendous amounts of money on only one child, while searching for the last possibility for a cure, or if that is not possible, alleviation. We do so not only as an investment in the health of one child or in the wellbeing of its parents but also for us. We make an investment in our personal lives, in our community, and more importantly, in ourselves as a mature society. Caring for our children with love and passion and fighting for their health and their life, fiercely and with reason, is an essential part of this investment. This complex commitment to one child on the part of so many is precisely the subject of this book. Nelson Mandela said it best: “There can be no keener revelation of a society’s soul than the way in which it treats its children.”