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# Pediatric and Congenital Cardiac Care



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Steven E. Lipshultz • Peter C. Laussen  
Editors

# Pediatric and Congenital Cardiac Care

Volume 1: Outcomes Analysis

 Springer

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*We would like to dedicate this book to all patients receiving pediatric and congenital cardiac care and their families. Each of the Editors would like to make the following additional dedications:*

*To Elijah, to Tore, to Harrison, and to the love of my life, Julie, who makes it all possible.*

Paul R. Barach

*To my parents David and Marilyn Jacobs for giving me the opportunity, to my wife Stacy for supporting and loving me, to my children Jessica and Joshua for making me proud and motivated, and to my patients, who represent the rationale for this initiative.*

Jeffery P. Jacobs

*To my wife Tracie and our children Hannah, Zach, Emma, and Sarah, who have always inspired me to do everything possible to improve the health of children. Their motivation has guided me, in the words of others, to “treat every child and family I have the privilege to care for as if they were my first and every day that I am entrusted with their care as if it was my last.” These volumes are part of the covenant I have made with many patients and their families to do our very best for them and those who follow. This has been made possible by the wisdom and collaboration of my cherished colleagues and mentors.*

Steven E. Lipshultz

*To Julia and Joan for their wisdom, guidance, and love. To my children and precious Emery, an inspiration for the future. To the patients I care for and who teach me every day.*

Peter C. Laussen



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## Foreword

A parent taking a child into hospital for diagnosis and treatment hopes for a cure and the restoration of a normal quality of life in the future. They fear many things, ranging from the worst—the death of the child—through their pain and suffering to uncertainty about how to manage the complexity of their own lives, which have so suddenly been disturbed. What they have a right to expect is that the people treating their child know what they are doing, are well trained, and particularly will put the needs of their child at the center of their decision making.

They are handing over their precious bundle of joy to strangers to care for, aware that that very care might actually threaten the life of that child as well as offer treatment. They are *loaning* their child to these professionals. It demands an enormous amount of trust to do that. As professionals, we need to be able to recognise that level of trust and repay it. Trust is a two-way thing.

The remarkable fall in the mortality for repair of congenital heart defects over the last 60 years could lead to complacency. But we must not forget that mortality is only one outcome measure and cannot reflect all the issues which concern parents. Medicine is dangerous. Many readers will have seen the famous diagram which charts the relative risk of accidents affecting users of organisations, which shows that there are high-reliability organisations like European railroads, western airlines and the nuclear industry but that medicine is about as safe as bungee jumping. This is due to errors that we make, problems we fail to address, complications we fail to tackle. There is no room for complacency if we want to deserve the trust of the parents who have loaned us their child.

If it were my child being treated, this is what I expect:

- I *expect* that my child will be cared for safely in a modern hospital.
- I *expect* my child to be looked after by a well-functioning multi-disciplinary team.
- I *expect* the staff will know the results of the treatment they propose not just in the literature but in their own hands.
- I *expect* the staff to know the complication rates in their hospital and put in place ways to reduce them.
- I *expect* that they will be collecting complete and validated data on all they do and that they will share those data openly with other professionals and the public.

- I *expect* the staff will do all they can to mitigate the certain human error that will occur, by putting in place systems which limit both risk and harm.
- I *expect* that the staff will be honest, open and transparent in all their dealings with me and that if they don't know something, they will say so and let me get a second opinion.
- I *expect* to be involved in decisions about the care of my child and to have my views respected.
- I *expect* that any harmful incident will be fully, openly and honestly investigated as quickly as possible and that learning from the incident will spread widely so that no one else can suffer.
- I *expect* that the team will be interested in the long-term outcome of treatment, not just in hospital, and that they will have mechanisms in place to gather the relevant information.
- I *expect* the truth and to be treated as if I were a friend, with warmth and empathy.

The Editors of this timely book have gathered an array of experts to give guidance as to how these expectations should be met. They give valuable insight into methods and use their own experience to highlight what we can do to be better. Being better, continuous improvement is what it is all about. Our speciality has done well with a relentless pursuit of excellence and is further advanced than many in being open about its results. Yet, it has much to learn from other disciplines, particularly oncology, about the benefits of collaboration over competition. Our discipline was built on the drive and energy of highly competitive alpha males and the disruptive technology of cardiopulmonary bypass. A second wave of disruption has followed the introduction of trans-catheter interventions. But this too has resulted in the same kind of rush to glory that we saw in the 1970s with surgical heart valve implementation and design. We need good studies, strong data and multi-center collaboration if we want to give the best care as quickly as possible.

This book exemplifies the move to collaboration and the drive towards openness and transparency. All our patients and their families are now 'digital natives'. They access the collective memory of Google just as we do. They expect to see our results and can quickly find their way around PubMed. We have a duty to give them insight into the facts they can read. The information provided in this text will help units realise both the importance of good data but also the methods by which it can be used, evaluated, interpreted and reported.

Don't forget, your duty is to keep the child safe and make it as well as you can. This book will help.

London, UK

Martin Elliott, MD, FRCS



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## Preface

The idea that clinical data could be analyzed by multiple congenital heart centers was shared by many enlightened individuals who foresaw the utility of such an organizational structure in the early 1980s. Discussions led to ideas that resulted in primitive data collection systems that catalogued diagnoses, procedures, complications, and survival statistics. The difficulty with these systems was that the nomenclature was not uniform and the challenge of comparing diagnoses and procedures prevented accurate analysis. In short, nomenclature categories were diverse owing to substantial and justified differences of opinion by many leading anatomists. Parallel publications by surgeons and cardiologists resulted in more uniform parochial nomenclature systems, but still there were significant differences between the two that challenged future collaborative efforts. The call to arms was answered by concerned clinicians and anatomists and resulted in a computer mapping strategy that was successful in categorizing diagnoses and procedures by what is actually described and performed and not by what it is called. As a result, the types of ventricular septal defects, atrial septal defects, truncus arteriosus, and the like now had a computer number and not a name. It was revolutionary in concept and comprehensive in scope. It was as if the world had one language even if the cultures varied. Before long, North and South America, Europe, Asia, and Africa were using the standard nomenclature.

This was just the beginning. Data were collected, analyzed, and interpreted to reveal or contradict theretofore clinical assumptions, biases, and largely undocumented hearsay conclusions. Data verification strategies by professional volunteers were planned, and audit visits were instituted. Concurrently, participating center data were to be assessed and compared with the combined experience of the participating centers. This allowed the possibility of program assessment and quality improvement. Complexity scores were developed based on Delphian principles until the time that enough data were collected to allow data-driven risk stratification.

The subsequent analysis of the databases and the developed nomenclature became exponential. Government agencies accepted the documents and instituted registries based on the developed principles. Long-term outcome analyses became a reality with database linking to both the Department of Health and Human Services Centers for Medicare and Medicaid Services Database and the Social Security Death Master File. Ethical issues were being discussed and used to clarify rules and regulations. In addition to these innovations, database documentation of complications has been used to guide

the clinician to perform more extensive data-driven informed consent. In an interesting twist of phrases, the database was used to inform the informed consent process.

The benefits of the database systems and the supporting nomenclature were simply too much to document in an expanded treatise. It could only have been accomplished by a book, the like of which is offered in this informative and excellent text. The reader will enjoy this book not only for the rich references that accompany the prose but also for the enjoyable historical account of what some people refer to as simply unbelievable.

Orlando, FL, USA

Constantine Mavroudis, MD

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- Our authors represent an international community of scholarship, with chapters written by luminaries and cutting-edge thinkers.
- All the family members of these authors are indeed owed a debt of gratitude because writing chapters markedly decreases the time available with them.
- Finally, this set of textbooks is possible only because of the tremendous efforts of our administrative staff and the Editorial and Publishing team, and we especially acknowledge the coordination throughout this project by Mitzi Wilkinson and the hundreds of hours devoted to this project by Flora Kim and Grant Weston.



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