Contents

Part I  Introduction to Patient and Family-Centred Care

1  Paediatric Patient-Centred Care: Evidence and Evolution .................... 3
   David B. Nicholas, Krista Keilty and Karima Karmali

2  A Canadian Perspective on a Child’s Consent to Research
   Within a Context of Family-Centred Care: From
   Incompatibility to Synergy ...................................................... 19
   Linda Sheahan, Michael Da Silva, Christine Czoli
   and Randi Zlotnik Shaul

3  Resource Allocation in Paediatric Patient
   and Family-Centred Care ....................................................... 35
   Jennifer L. Gibson

Part II  Legal, Ethical and Cultural Considerations

4  Culture, Religion, and Family-Centred Care ................................. 57
   Rani H. Srivastava

5  Ethical and Legal Issues in Patient and Family-Centred
   Care: Canadian First Nations, Métis and Inuit People ....................... 79
   Julija Kelečević

6  Accounting for the Family in Law: An Impartial but not
   Impersonal Point of View ......................................................... 97
   Lee A. Chapman

7  Legal Considerations in Paediatric Patient and Family-
   Centred Healthcare .................................................................... 115
   Joan M. Gilmour
### Part III  Implementation and Lived Experience

8  Paediatric Patient-Centred Care at SickKids: Advancing Child & Family-Centred Care  
Krista Keilty, David B. Nicholas, Karen Sappleton and Karima Karmali  
129

9  The Effect of Patient and Family-Centred Care (PFCC) Delivery Model on Paediatrics at the Thunder Bay Regional Health Sciences Centre  
Bonnie Nicholas  
145

10  Creating Partnerships for Life: One Family’s Story of Paediatric Patient and Family-Centred Paediatric Care  
Janis Purdy  
157

11  Supporting the Developing Autonomy of Youth Patients: Reflections on the Role of Healthcare Providers  
Christy Simpson  
175

### Part IV  In Context

12  Participation in Paediatric Research Studies  
Nancy Walton  
187

13  Clinical Genetics Practice: Integrating Paediatric Patient and Family-Centred Care  
Cheryl Shuman and Riyana Babul-Hirji  
209

14  End-of-Life Decision-Making in the Neonatal Intensive Care Unit: Serving the Best Interests of the Newborn within a Family-Centred Care Framework  
Jonathan Hellmann  
221

15  Legal and Ethical Issues in Child-and Family-Centred Care: Transplantation  
Rebecca Greenberg, Michael Campbell and Linda Wright  
245

16  Patient and Family-Centred Care: Critical Partnerships when Treating Adolescent Anorexia Nervosa  
Lori d’Agincourt-Canning, Lucinda Kunkel and Karen Dixon  
269
17 Lost in Transition: Legal and Ethical Approaches When Applying Patient- and Family-Centred Care to Adolescents with Disabilities ................................................................. 289
Maria L. Z. McDonald and Lucie Wade

18 Ethical Conflicts that may Arise When Caring for Dying Children .......................................................... 321
Christine Newman, Adam Rapoport and Gurjit Sangha

Afterward ........................................................................................................... 337

Index ................................................................................................................. 339
Paediatric Patient and Family-Centred Care: Ethical and Legal Issues
Zlotnik Shaul, R. (Ed.)
2014, XXV, 346 p. 24 illus., Hardcover
ISBN: 978-1-4939-0322-1