# Contents

## Part I  Introduction to Patient and Family-Centred Care

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

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

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

## Part II  Legal, Ethical and Cultural Considerations

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

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

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

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

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

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

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

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

Part IV  In Context

12 Participation in Paediatric Research Studies  ................................................................. 187
    Nancy Walton

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

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  ................................................................. 221
    Jonathan Hellmann

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

16 Patient and Family-Centred Care: Critical Partnerships when Treating Adolescent Anorexia Nervosa  ................................................................. 269
    Lori d’Agincourt-Canning, Lucinda Kunkel and Karen Dixon
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