

# Forward

This collection of essays marks an important step in the evolution of the concepts or models of paediatric patient-centred care and family-centred care. While there is still no consensus in the healthcare literature on the definition of these terms, there is sufficient recognition of relevant values, to allow for the consideration of definitional options and their application across Canadian geography and healthcare settings. In an increasingly regulated healthcare system, providers, administrators, patients, families and regulators must be attuned to the legal and ethical tensions and synergies between concepts and models publicly endorsed to serve as guidance for care.

In this text, traditional themes in health law and paediatric bioethics are engaged in an attempt to provide an in-depth appreciation of the opportunities and challenges posed by the application of patient-centred care and family-centred care in a variety of clinical paediatric contexts.

Together the authors represent an exceptional group of clinical ethicists, lawyers, researchers, parents, healthcare providers, counselors and trainees with both theoretical and real life hospital-based experience. While one chapter revisits my earlier collaboration exploring the relationship between patient-centred care and family-centred care in the context of consent to research, all other chapters were written specifically for this text.

Contributors were asked to consider key strengths and challenges of working with the models of paediatric patient-centred care and family-centred care. Are there tensions and synergies between these models? How are these concepts understood and used within specific contexts? Based on experiences to date, are there any issues that warrant further research? Through their essays, the contributors provide instructive reflections on these issues from their unique vantage points, further developing both the theory and application of the models.

This collection contributes to a constructive discussion about the future of paediatric patient-centred care and family-centred care. These engaging and provocative essays reflect these models of paediatric healthcare within a particular social and historical period in Canada, and within a variety of distinct treatment settings. Notwithstanding the fact that the chapters were written as independent entities, the common goal of providing accurate current descriptions of these models in practice as well as rigorous analysis of the ethical and legal implications of their application, is a connecting feature that threads through them all.

While this book focuses on the Canadian context, the case descriptions and analyses are pertinent internationally. To date, most of the patient-centred care and family-centred care literature has come from the United States and England. Because the values these concepts represent are relevant in international healthcare contexts, there is much benefit in considering their nature and application within a distinct legal system and socio-political healthcare setting. While many countries approach the legal and ethical issues addressed in ways that are similar to Canada, there are some distinct approaches grounded in the laws and policies unique to each jurisdiction. Readers engaged with paediatric healthcare outside of Canada will need to be cognizant of laws specific to their own setting and use the Canadian examples as inspiration and at times cautions. Examples of two relevant and distinguishing features of the Canadian context are the quasi-socialized funding of healthcare services in Canada as well as the legal frameworks of informed consent.

This book is intended to be both theoretically and practically useful. The theoretical aims are to help readers tease out the meaning and significance of these models, the extent to which it is defensible to interpret them as conceptually consistent, the extent to which real life circumstances reveal their inconsistencies and contexts where the separate models can combine as a hybrid model of care. The chapters include references to clinical and research-based cases that highlight the theoretical concepts being discussed. The cases discussed, allow readers to engage with the real-life circumstances in which the models are applied. The models of paediatric patient-centred care and family-centred care were never intended to be purely theoretical abstractions but rather to serve as frameworks to guide those working in healthcare organizations.

This book was prepared with the needs of practicing clinicians, allied health professionals, policy developers, hospital administrators and educators in mind. On a practical level, the book aims at maximizing the potential benefits of these models and addressing the ethical and legal challenges they can create. The goal is to support those working at applying these models in healthcare organizations and to serve as an educational resource for trainee education. It may also be helpful for researchers and students in non-clinical disciplines interested in philosophy, law, health policy, health administration and management. The book provides a unique window into how operationalizing values at the clinical interface, has implications for theory and organizational frameworks. While the focus of this book is the Canadian paediatric context, the relationships, duties and lessons discussed are germane across the age spectrum.

This book is made up of nineteen chapters divided into four parts. The chapters can be read sequentially linked thematically or used as a reference by those interested in specific topics.

The chapters in Part I provide an introduction to patient and family-centred care that reviews its evolution to both distinct and hybrid models of care. In Chap. 1 David B. Nicholas, Krista Keilty and Karima Karmali examine the evolution and literature on paediatric patient-centred care with a focus on child and family-centred care. While the authors acknowledge that evidence for child and family-centred care is limited, they demonstrate how the literature increasingly reveals the positive impact

it has on outcomes and processes related to general health, mental health, well-being, satisfaction and family functioning. In Chap. 2 Linda Sheahan, Michael Da Silva, Christine Czoli and I discuss the values underpinning two major trends in paediatric bioethics. We propose a model for obtaining consent for paediatric research in a context that recognizes the family relationships of paediatric research participants, as well as the participants' emerging autonomy and rights. In Chap. 3 Jennifer Gibson explores the implications of paediatric patient and family-centred care on resource allocation processes and decisions at the micro (clinical) and meso (organizational) levels in paediatric healthcare settings. In this chapter she argues that the core principles of paediatric patient and family-centred care are not only consistent with many new approaches to resource allocation, they may also assist healthcare organizations in better mobilizing their limited resources toward providing high quality healthcare.

The chapters in Part II focus on legal, ethical and cultural considerations. In Chap. 4 Rani Srivastava examines paediatric family-centred care through the lens of religious and cultural diversity. She contends that reframing our conceptual understanding of family-centred care and its corresponding competencies through the lens of cultural competence offers significant promise for paediatric healthcare. In Chap. 5 Julija Kelečević uses narratives reflecting Aboriginal and non-Aboriginal perspectives as the basis for exploring the common ethical and legal challenges that Aboriginal people face in healthcare decision-making. She also compares the concepts of Western bioethics and Aboriginal values and discusses them within the developing models of patient and family-centred care in the paediatric setting. Kelečević presents paediatric patient and family-centred care as a mechanism for providing care that is consistent with patients' wishes. In Chap. 6 Lee A. Chapman examines the tension that can surface when the more collaborative nature of family-centred health care confronts the representation of individual legal rights, particularly the rights of children in legal disputes. She highlights for readers the significant distinction in law between an impartial and impersonal point of view. In Chap. 7 Joan M. Gilmour traces some of the ways in which the law both affirms and limits the model of paediatric patient and family-centred caregiving. She considers the legal issues that result when responsibility for care is shared or delegated to parents, family members or the patient and highlights important considerations to promote sustained delivery of safe, quality care.

The chapters in Part III provide 2 examples of internationally recognized hospital-based implementation of paediatric patient and family-centred care, a chapter highlighting the vantage point of the parent and another highlighting the vantage point of healthcare providers. In Chap. 8 Krista Keilty, David B. Nicholas, Karen Sappleton and Karima Karmali present an overview of how Child and Family-Centred Care is currently implemented at The Hospital for Sick Children (SickKids). It describes historical influences and impactful innovative practices led by staff and families at SickKids. In Chap. 9 Bonnie Nicholas describes the Thunder Bay Regional Health Sciences Centre's Patient and Family-Centred Care model, using paediatrics to illustrate how Patient and Family-Centred Care and Patient and Family Advisors, in particular have significantly improved patient and family care. In Chap. 10 Janis Purdy provides a firsthand account of her family's experience with

paediatric patient and family-centred paediatric care told from her vantage point of being a parent of a paediatric patient. In Chap. 11, Christy Simpson discusses the need for both changes to, and transitions in, how healthcare is provided for youth, so as to correspond to the development of their abilities to make their own health decisions. This chapter explores several issues related to this transition period both in the context of providing care for youth patients with chronic illness and from the perspective of the role of healthcare providers and their relationships with youth patients and parents.

The chapters in Part IV examine the current application of paediatric patient and family-centred care in a variety of complex health care contexts. In Chap. 12 Nancy Walton discusses general guidelines in place in Canada for the ethical conduct of research, and how the two approaches of patient-centred care and family-centred care may provide some valuable insights to deal with ethical concerns regarding recruitment, informed consent and protection of privacy in paediatric research. In Chap. 13 Cheryl Shuman and Riyana Babul-Hirji discuss genetic counseling in the context of patient-centred and family-centred care and whether patient-centred care is just a point on the family-centred care spectrum. They highlight the need for a healthcare model that in the genomic era of personalized medicine, can best shape clinical practice guidelines for optimal patient and family care. In Chap. 14 Jonathan Hellman explores how the recognition of the stress endured by parents of infants in the neonatal intensive care unit has led to the ready adoption of a family-centred care approach to neonatal care. He emphasizes the clarity arising out of mutually derived decisions in which all parties are empowered, the preferences established and where dialogue and negotiation have achieved resolution. In Chap. 15 Rebecca A. Greenberg, Michael Campbell and Linda Wright, critically examine ethical issues in the domain of paediatric organ transplantation through the lens of paediatric patient and family-centred care. They provide rich examples from the field of transplant. They highlight tensions between the models of care and circumstances where they may work synergistically in pursuing the goal of determining when it is medically and ethically appropriate to offer transplantation to children. In Chap. 16 Lori d'Agincourt-Canning, Lucinda Kunkel and Karen Dixon explore ethical considerations related to treatment refusal by adolescents and/or their parents, including respect for autonomy, parental decision-making authority and the duty to protect patients from harm. With a focus on anorexia nervosa, they provide practical approaches to promote continued engagement with the patient and family when there are discrepant views of what is in the best interest of the adolescent. In Chap. 17 Maria L.Z. McDonald and Lucie Wade explore the challenge of providing treatment within a patient and family-centred care model, when a capable adolescent with a disability disagrees with her mother about a proposed service. Their analysis of the legal and ethical obligations of health practitioners, adolescent patients and family includes attention to adolescent human rights and the social model of disability. In Chap. 18 Christine Newman, Adam Rapoport and Gurjit Sangha use cases created by merging actual clinical experiences, to explore the potential divergences created by a patient-centred and family-centred approach to the care of a dying child, while offering suggestions on how to resolve these conflicts.

I feel honoured to have worked with such an esteemed group of contributors in preparing this collection of essays. My hope is that this text will be useful in furthering the theoretical development of paediatric patient-centred care and family-centred care, practically useful for those in healthcare organizations working to operationalize these models and that it will act as a catalyst or springboard to further study in Canada and internationally.

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