Family-Centered Care in a Pediatric Context: Addressing Conflicts and Complexities

Randi Zlotnik Shaul JD, LLM, PhD
Director Department of Bioethics
The Hospital for Sick Children
Toronto, Ontario, Canada
The Lens I Bring

- Bioethicist in tertiary care pediatric hospital over 16 years
  - Past 5 years, Director Department of Bioethics
  - Before graduate studies in Bioethics, a lawyer with Ontario’s Ministry of Health
    - Interested in ethical and legal frameworks that inform how health care should be delivered
- My research and scholarship in areas where tension between the norms people turn to for guidance in complex health care situations
Case

- A social worker came to me concerned about a mom telling her that her daughter was going to be getting married in the mother’s birth country – when the family attends the wedding, the mom’s young son (bride’s brother) would be sharing a room with the groom’s young brother.

- Notwithstanding their son’s severe asthma, the parents decided not to take with their son’s asthma medication.
  - “If the groom’s family discovered there was severe asthma in our family, the wedding would be called off.”

- News about the severe asthma would negatively affect the marriageability of this daughter as well as the other children.
Social worker felt she could not challenge the parents’ plan because family-centred care called on her to respect the family’s values.

The ethical tension she felt was because respecting the family’s values felt like being complicit with something that was not in the child’s best interests.
Family-Centred Care in a Pediatric Context: Addressing Conflicts and Complexities

Objectives

• Describe the development of family-centred care (FCC) in pediatrics
• Analyze the tensions and complexities of applying FCC in a paediatric setting
• Formulate strategies for retaining the strengths and minimizing the vulnerabilities associated with FCC in such a setting
Development of FCC

- A relatively modern concept in Bioethics scholarship
- A model of health care delivery that has evolved over time in an attempt to optimize pediatric care
- Evolved in response to recognizing that acting in a child’s best interests requires shared decision making with families & respect for the family context and values
Snapshot of Western Pediatrics History

• Historically children property of their fathers
• Industrial revolution`s separation of work and home, led to new conceptions of family and children
• Notion of ‘childhood’ central to a flourishing family
• From agrarian role as participant in production to one of consumption (Kopelman 2010)
• Recognized children as having interests with corresponding legal rights to a threshold of care
Evolution cont’d

- By early 20th century recognition that children can benefit from care provided by specialty trained experts
  - 1933 American Board of Pediatrics
- In 1960s increased support for decision making rights of patients
  - Parents having more say re children’s health care
- More recently attention to child rights has emphasized parent/surrogate decision maker duties to act in child’s best interests and for mature minors to be their own decision makers
Clinicians, administrators, bioethicists in North American health care organizations caring for children, challenged by how to appropriately recognize the significance of family while providing care that centers on the pediatric patient.
**Distinguishing Models of Care**

- **Patient-Centered Care:**
  - Traditional legal and ethical model whereby health care provider is guided by fiduciary relationship with patient

- **Family-Centered Care:**
  - No single definition
  - Common goal of acting in best interests of the patient through respect for the family’s values and context
Family-Centered Care

• Family-centered care assures the health and well-being of children and their families through a respectful family-professional partnership - Maternal and Child Health Bureau

• 4 principles of FCC:
  1. Dignity and respect
  2. Information sharing,
  3. Participation and
  4. Collaboration

- The Institute of Family Centered Care
Benefits of FCC

• Emphasizes interdependent relationships in the clinical context
  • Effects of a decision on all family members, and the special vulnerability of the pediatric patient (AAP 2003)

• The emphasis in language on *family* rather than *individual*, resonates as appropriate in many cultures

• Especially comforting in many multi-cultural health care settings
Relational Ethics

- Patients come to hospital with their physical selves, their psychological selves and their social selves.
- When we speak about caring for the whole person – “do we expect patients to leave anyone or anything that is not a body part at the door?”
Widespread Adoption of FCC

• Notwithstanding fact that good patient-centered care necessitates consideration of family context, significant success has come from putting family front and center.

• Given significance of family to well-being of children, many pediatric health care organizations moved from philosophy of patient centered care to family centered care.

• Values reflected in their policies, public materials, logos.
Values Through Logos
Tensions and Complexities

• For many cultural groups, a care model that calls for a focus on the significance of the family unit, rather than the individual patient, feels familiar, appropriate and comforting

but

• While in pediatric settings, FCC may be appreciated by families and support respect for the unique family units in which children are generally situated, the legal and ethical fiduciary duties of clinicians are to patients
Implications of Language

• Commitment *family-centred care* model this can create uncertainty amongst staff (and families) as to where the primary obligations of staff lie
  • to the patient or to the family
• Some pediatric settings speak of *child and family-centered care*
• When what HCP considers in the best interests of the child different from what family sees as best interest of the family or the child, tensions and complexities arise
Synergy or Tension?

- When interests of the family and patient are aligned, the models of *family-centered care* or *child and family-centered care* are praised.
- When interests do not align, the lack of agreed upon definitions or application becomes a source of challenge.
Language Conflict

• Clinicians in pediatrics expected to focus on the best interests of the child through a lens that puts patients at the center while

• Also seeking the best interests of the child through model that speaks of family as being at the center
Significance of Terminology

- Debate over the extent to which the distinct terminology is actually intended to reflect a distinct focus
  
  - If both models are mechanisms to act in the BI of the child, easily to operationalize

  - If models intended or interpreted as having distinct foci, risks very real
Fours Risks

• Inappropriate recommendations where clinicians are unsure of the ethical and legal implications of the model(s)

• Diminished trust by patients and families in the clinician-patient or clinician-family relationship

• Lack of clarity re what organizational leaders should reasonably expect of staff

• Moral uncertainty and distress for all parties
Challenging Examples in Canadian Paediatric Context

1. Parent wants to participate meeting to discuss medication change
   • Can only attend after sibling’s parent-teacher interview

2. Family’s cultural norm has eldest male relative as decision maker until patient has completed puberty
   • Adolescent clearly capable / mature minor

3. Post transplant patient needs weekly follow-up
   • Parent risks job-loss if takes more time off

4. Chemotherapy has 90% chance of cure
   • Family believes in Traditional Healing
Tracking Through Seminal Cases

- Tension between the deference that should be given to families versus pediatric patients has a long history in healthcare.

The Doctor by Luke Fildes (1884-1927)
Key Features of Many Cases

- While parents generally assumed to be acting in child’s best interests

  - “We may not always be convinced that a specific parental decision accomplishes that goal”
    (Diekema, Mercurio & Adam Clinical Ethics in Pediatrics)

- Recurring theme to identify limits of parental decision-making authority
  - When a parental decision should be challenged
Landmark Legal Decisions

- **Jodie and Mary** *(Re A (conjoined twins) [2001] 2 WLR 480)*
  - Role of parents, best interests of each child vs family’s values

- **Ashley X** *(Washington Protection & Advocacy System investigation)*
  - Best interests of the child vs interests of family

- **JJ** *(Hamilton Health Sciences Corp. v. D.H., 2014 ONCJ 603 + amendment)*
  - Cultural interests vs biomedical interests
Retaining the strengths and addressing the vulnerabilities of Family-Centered Care in pediatrics
Child & Family-Centered Care

• Most often synergy between pediatric patient-centered care and family-centered care
  • Inspired by the real life ethical and legal challenges
    • when a patient-centered approach leads to different recommendation from a family-centered approach
• Theoretical and practical discussion of the issues
• 31 authors from across Canada, across disciplines
  • resource allocation, culture, research, genetics, neonatology, transplantation, chronic illness, eating disorders, end of life
Relational Autonomy Theory

- Personal autonomy primarily depends on social relations
  - Our development as individuals is driven by our dependence on and/or interaction with others

- Research needed on these models exploring the moral content and consequences of family expectations and relationships
  - Layers of power dynamic, social norms, expertise, communication styles…
Frameworks for Decision Making in Paediatrics

- The triadic relationship
  - clinician, patient and parent/guardian
- Shared decision making
- Physicians and parents and co-fiduciaries (Laurence McCullough)
- Child and Family-Centred Care
Recommendations:

- Develop clarity in pediatric health care organizations about the expectations intending to convey regarding duties to and rights of families
- Ensure institutional policies and materials distributed to the public are consistent with ethical and legal fiduciary obligations to pediatric patients
- Effective interpretation of C&FCC has the child at the center with family central
  - When the wishes of the family conflict with the interests of the child, notwithstanding an organizational care model of family-centered care, primary obligations are to the pediatric patients
Summary Thoughts

• For clinicians to be able to defend the substance and process of recommendations, essential to appreciate the implications of health care models of patient-centered care and family-centered care.
• Finding this challenging is not a result of not seeing things clearly, but rather a function of seeing the complexities or lack of synergies for what they are.
• At the heart of most pediatric bioethical issues are fundamentally important questions related to our human relationships

• Cases involving tension between the rights and obligation to pediatric patients and families challenge us to be clear about our assumptions and existing standards

• Our actions or inactions today will have far-reaching effect
  • Nature of the clinician-patient relationship, evolving role of family, security of society’s mosaic
Outstanding questions

• Who gets to count as family?
  • Grandparents, aunts, often vocal and have unique needs
  • “It takes a village to raise a child”
• How can we foster adolescent development within FCC?
• We are born in relation, attachment parenting and many cultures nurture the connections rather than seek independence – does it make sense to have fiduciary responsibility so focused on the individual?
  • Or do we need to refocus and be clear that patient focus will necessitate family considerations?
The Future of Family-Centered Care

• Are we asking parents to put aside their other responsibilities and unfairly asking them to only focus on the 1 child?

• From your vantage point – what should we be thinking about as we move ahead being sensitive to the context of the child within the family?
Thank you