

American Medical Association Journal of Ethics

January 2016, Volume 18, Number 1: 3-5

FROM THE EDITOR

"Nothing About Us Without Us": Toward Patient- and Family-Centered Care

Around dinnertime on the second Tuesday of every month, a group of people gather in the Family Center at C.S. Mott Children's Hospital in Ann Arbor, Michigan. Some are former patients, some are staff, and most are parents of pediatric patients, some of whom are deceased. They have been invited to share their perspectives and to help improve administrative decision making and care delivery.

I was first introduced to the concept *patient- and family-centered care* (PFCC) by this patient- and family advisory council (PFAC), an advisory body that promotes the inclusion of patient and family member perspectives in making organizational and practice decisions. As a student member over the past year, I've observed the dedication of these council members to improving health care culture by promoting PFCC values.

PFCC is built upon four fundamental principles: treating patients and families with respect and dignity, sharing information, encouraging their participation in care and decision making, and fostering collaboration in care delivery and program design, implementation, and evaluation [1]. At its core, PFCC is about including patients and families in all aspects of health care. As part of a broader movement towards participatory medicine that advocates for collaborative partnerships in health care [2], PFCC means developing partnerships with patients and their families; recognizing their expertise by involving them as members of clinical care teams, advisory committees, and regulatory research boards; and promoting inclusion of patients and their loved ones in bedside and systems-level health care dialogues. Physicians can learn from patients and their families, and it is our responsibility to do so.

I first became interested in better understanding patients' perspectives as an English major exploring disability studies and narrative medicine; I sought to understand persons' health care experiences through their narratives. PFCC models of thinking encouraged me to broaden my scope and to appreciate the interconnectedness of patients' and family members' experiences. Although PFCC originated in pediatrics, the importance of families extends to all medical practice [3].

As I learned more about the tenets of PFCC and the many forms that PFCC takes in practice, I began to wonder about when and how striving to deliver inclusive care can be ethically complex. How should medicine accommodate families alongside patients, and what ethical challenges arise when trying to do so? Accordingly, this theme issue of the

AMA Journal of Ethics considers some of the ethical challenges of implementing PFCC. In an attempt to make this issue as “patient- and family-centered” as possible, I invited feedback from the Mott PFAC and included patients and family members as authors.

This issue aims to define and contextualize PFCC, particularly for those to whom this set of ideas is new. [One article](#) outlines fundamental principles of PFCC [4]. [Another](#) considers the history of PFCC and what the ideological shift from paternalism to shared decision making requires of patients, their loved ones, and their clinicians.

Some health care professionals might resist PFCC models of practice because they suspect that PFCC endorses unattainable ideals. So, contributors to this issue illuminate the feasibility of PFCC as a standard model of service delivery. For example, [two articles](#) discuss the University of Pittsburgh Medical Center PFCC Methodology and Practice, a six-step, replicable method for integrating PFCC principles into clinical and organizational practice.

Three cases introduce ethical questions about implementing PFCC. [How](#) should clinicians respond when a patient’s medical needs demand sacrifices of family members? [How](#) should clinicians handle patients and family members’ conflicting end-of-life care goals? And how ought clinicians to reconcile pluralism in colleagues’ understandings of what it means to provide PFCC? This month’s [roundup](#) of relevant opinions from the *AMA Code of Medical Ethics* points readers to guidance on managing conflicts among family members and the family’s role in decision making in intensive care.

Two articles discuss systems-level promotion of PFCC models of care. In the medical education section, University of Michigan staff [describe](#) how they collaborated with faculty and with patient and family advisors to create innovative courses on PFCC principles for first-year medical students. [Another article](#) sheds light on how the physical structures of intensive care settings influence openness and collaboration among clinicians, patients, and family members.

Finally, two contributions address PFCC advocacy. Our podcast interviewee [discusses](#) her experiences on PFACs and the impact that these advisory bodies can have on care. A patient advocate and artist [shares](#) her work representing patients’ and family members’ health care experiences and discusses the positive policy-level impact such representation can generate. A doctor contributes his [reflections](#) on learning patient-centeredness through volunteer work.

In assembling this theme issue of the *AMA Journal of Ethics*, “Promises and Challenges in Patient- and Family-Centered Care,” my hope has been that delving more deeply into ethical considerations inherent in PFCC generates fresh insights into and broader understanding of how PFCC can enhance healing.

References

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Acknowledgements

I would like to thank Dr. Arno Kumagai, as well as Dr. Andrew Barnosky, Dr. Christian Vercler, and Dr. Kathryn Moseley, for their mentorship and support throughout this process. I also wish to thank the contributing authors and the *AMA Journal of Ethics* staff for their patience, encouragement, and dedication to this issue. Finally, I would like to express my gratitude to members of the Mott PFAC—and to all patients and families that I have spent time with at Mott—for helping me to realize how important it is for both patients and families to be at the center of care.

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ISSN 2376-6980**