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Patient- and Family-Centered Care: A Systematic Approach to Better Ethics and Care

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The current AMA *Code of Medical Ethics* contains six sections of formal opinions on the patient-physician relationship. That portion begins with a reference to a “mutually respectful alliance” [1]. This type of alliance is an integral part of [patient- and family-centered care](#) (PFCC).

PFCC (sometimes known as simply “patient-centered care”) emphasizes respect for patient values in individual care decisions as well as the role of patients and families as advisors and essential partners in improving care practices [2]. It is characterized by a two-way partnership, the importance of which is growing with the movement from payment for volume to payment for value. As just one example, under the Medicare Access and CHIP Reauthorization Act (MACRA), part of physician pay is linked to patient and caregiver experience and to patient-reported outcomes [3].

The ethical power of PFCC, however, lies in its respect for patient autonomy and opinions. PFCC represents a change in organizational culture that has a powerful ethical resonance, as “behaviors associated with patient-centered care, such as respecting patients’ preferences, should be justified on moral grounds alone” [4]. Yet it is also one that a systematic evidence review has linked to the ethically desirable goals of improving a broad range of patient safety and clinical effectiveness outcomes [5]. The literature suggests that patients who are engaged in their care have “better health outcomes and incur lower costs” [6].

One approach to PFCC, which invites patients and families (however the patient chooses to define that term) to be catalysts and partners in changing the entire care process, is the [Patient- and Family-Centered Care Methodology and Practice](#) (PFCC M/P). Developed at the University of Pittsburgh Medical Center (UPMC) by Anthony M. DiGioia (a co-author of this article) and his team, the PFCC M/P has been shown to effectively translate patient-centered care “from ideal to real” [7].

The Origins of the PFCC M/P

The PFCC M/P is a six-step approach. It has been influenced by the dimensions of patient-centered care proposed by the Picker-Commonwealth Program for Patient-

Centered Care, which was initiated in 1987 [8]. Picker-Commonwealth derived its categories from patient focus groups and emphasized their importance within an ethical context, noting that “respecting patients’ individuality is the foundation of humane medical care” [2]. The Picker-Commonwealth categories were described in a 2001 report of the Institute of Medicine (now the National Academy of Medicine), which asserted that patient-centered care constitutes one of the six goals of a twenty-first-century health care system [9]. Moreover, as Institute for Healthcare Improvement founder Donald Berwick has emphasized, patient-centeredness “is a dimension of health care quality in its own right” [10].

Acting ethically in a manner that improves clinical results is a central tenet of the PFCC M/P. The PFCC M/P adapts six dimensions of the Picker-Commonwealth domains into action steps and considers all health care experiences through the eyes of patients and families (see table 1). Importantly, there is accountability for patient-centeredness among not just doctors but everyone in the organization who affects a patient’s or family’s care experience.

Table 1. The six steps of the PFCC Methodology and Practice [11]

Step 1: Define the care experience for improvement, including the beginning and end points
Step 2: Create a PFCC Guiding Council to lead the effort and break down barriers
Step 3: Define the current state of the care experience through Shadowing, surveys, and other tools
Step 4: Expand the PFCC Guiding Council into a PFCC Working Group with representative from every “Touch point” of the care experience identified through Shadowing
Step 5: Write the ideal story, from the patient and family’s perspective and in first person
Step 6: Create PFCC Project Teams to close the gaps between the current and ideal state

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The Success of the PFCC M/P

The ethically sensitive approaches to patients’ experiences of care that characterize the PFCC M/P have led to improvements. For example:

North Carolina-based Wake Orthopaedics overhauled its pre-operative testing and education, prioritized patient-oriented communication, and redesigned its pain management pathway (a recurring patient concern). In just one year, the surgical

infection rate declined from 3 percent to zero, unplanned readmissions after elective primary knee and hip surgery declined from 6.2 percent to 3.6 percent, patient satisfaction jumped from 80 percent to 93 percent, and the average cost per patient fell from \$13,014 to \$12,074 [12].

Harvard-Vanguard Outpatient Women's Services, part of Boston-based Atrius Health, used shadowing and other tenets of the PFCC M/P to guide renovation of its [physical space](#) to provide more privacy to women being weighed and to improve staff collaboration [13] after learning that patients did not trust that clinicians were working as a team.

Royal United Hospital of Bath, England, applied the PFCC M/P to end-of-life care. Before implementation, clinicians lacked confidence in dealing with critically important decisions. Physicians lacked confidence in their ability to talk with dying patients and their families, nurses felt uncomfortable voicing opinions to doctors about treatment withdrawal, residents and fellows felt unsupported in decisions about when to treat and when to maintain comfort, and poor documentation was rampant. However, just nine months after implementing the PFCC M/P, the change in practice was extraordinary. The percentage of physicians documenting end-of-life discussions with every one of their patients went from zero to 100 percent, the percentage reporting discussions with the family jumped from 50 percent to 100 percent, and evidence of advance care planning being communicated to the primary health care team went from zero to 100 percent. In addition, the residents and fellows (called "junior doctors" in Britain) received mentorship and support from end-of-life and palliative care specialists [14].

Advantages of PFCC

Unfortunately, many clinicians still fear PFCC is a "touchy-feely" approach that will cost time, money, and additional resources. But the benefits of the PFCC M/P have generally been achieved in a matter of weeks by redirecting resources; no budget increase or new employees are needed. The process can also, as noted above, significantly reduce other expenditures on care [15]. Participating physicians spend perhaps one hour a week on the PFCC M/P instead of long hours working around broken processes and systems [16]. Moreover, as a research paper on building a patient-centered culture noted, "organizations need to see beyond the touchy-feely, nice-to-have component of the patient-centered care model and recognize that...[it] can result in significant improvements in clinical outcomes and cost reduction" [17].

In the PFCC M/P team's experience, although veteran clinicians are almost always skeptical at the beginning, they are generally won over after following the patient care journey (shadowing patients) and viewing the care process through the eyes of patients and their families. Moreover, clinicians have repeatedly told the PFCC M/P team that the process makes them feel better about their work. That shouldn't be a surprise: the PFCC

M/P process focuses on frustrations that confront both patients and families and those trying every day to help and heal them.

Even if some of the PFCC M/P terms are unfamiliar, its core idea expands upon Hippocrates' famous ethical injunction, "First, do no harm." One surgeon participant, for example, spoke of saving a patient's life in an emergency surgery and being chagrined to learn of avoidable harm during the process—not clinical harm, but harm nonetheless: the loss due to theft from the hospital of the patient's wallet, watch, and eyeglasses. The PFCC M/P methodology addressed that problem through a working group whose shadowing of the patient journey established the frequency and causes of the problem and then changed procedures (e.g., marking belongings more clearly and establishing staff accountability) so that patients no longer had to cope with the emotional or financial impact of a loss of important personal belongings [18].

Conclusion

Patient- and family-centered care is becoming an integral component of modern medicine due to forces from within the profession, as exemplified by the Institute of Medicine, and external payment pressures, such as the MACRA. The PFCC M/P approach is grounded in the ethical value of embracing patients and families as "essential partners." Its six steps systematize this ethical imperative by enabling clinicians to uncover issues important to patients that they might not otherwise recognize and, with patient input, devise genuinely patient-centered solutions. Because the PFCC M/P includes a last step for closing the gap between the "ideal" and "real" state of a process, it also establishes accountability. And it is scalable, able to be adapted throughout an organization in different settings. In that regard, it enables ethical good intentions to be systematically translated into ethical conduct by weaving continuous improvement into the fabric of every organization [19, 20].

Some 2,000 years ago the great Jewish sage Hillel posed this challenge: "If I am not for myself, who will be for me? If I am only for myself, what am I? If not now, when?" [21]. Patient- and family-centered care draws on the same ideas of advocacy and service, reminding all those involved in care, physician and nonphysician alike, of the ethical values that first drew them to this field and of the urgent need for action.

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Further Reading

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