

# AMA Journal of Ethics

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# American Medical Association Journal of Ethics

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## 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.

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## ETHICS CASE

### Could Good Care Mean Withholding Information from Patients?

Commentary by Benjamin D. Long and Andrew G. Shuman, MD

Every morning for three weeks, Isalita has sat at her patient Janet's bedside. As a third-year medical student on an oncology rotation, Isalita has the most time of anyone on the health care team to get to know her patients. Janet has talked to Isalita about her past medical experiences, both good and bad, saying that she appreciates physicians' being open and honest with her about her medical condition. She wants the chance to understand what is going on, she tells Isalita, even if in the end she asks for and takes the physician's recommendation.

Janet's oncologist, Dr. Haveford, has been seeing Janet since her initial diagnosis and treatment for breast cancer. They have a trusting and comfortable relationship with one another. Dr. Haveford pays particular attention to each of his patient's preferences and values. In Dr. Haveford's experience, Janet, when presented with a number of choices, has appeared uncertain and ultimately asked him what he thinks would be best for her.

Janet's cancer has now metastasized. Other than some clinical trials for which she might be eligible, Dr. Haveford does not think that more treatment will slow her cancer's progress, even though some available drugs might extend her life, and he believes that going through any of the available trials would likely diminish Janet's remaining quality of life. Moreover, he does not want to overwhelm her with details about clinical trial options, risks, and potential benefits. Knowledgeable and responsive patient-centered care in this instance, he thinks, means not telling her about clinical trials.

When Dr. Haveford discusses Janet's treatment options with her, Isalita is dismayed that he only presents Janet with a recommendation to pursue conventional options in combination with palliative treatment. She is uncomfortable with the idea of not sharing the clinical trial options with Janet, but she does not want to appear to be trying to undermine Dr. Haveford's authority or question his judgment.

## Commentary

Is Dr. Haveford's withholding information about clinical trials appropriate in this case and what are criteria upon which we might decide? Additionally, what should Isalita do?

## **Roles of Clinical Trials in Caring for Patients**

To resolve these questions, we must briefly re-examine the purpose of clinical trials. Clinical trials are research experiments designed to test the safety and/or efficacy of an unproven treatment. In order to justify the administration of unproven treatment modalities and the procedure of randomization, which might expose subjects to risk, the research ethics community has invoked the concept of clinical equipoise, whereby the efficacy or superiority of each trial arm is legitimately unknown [1]. Clinical trials, especially in early phases, are designed to help future patients, not the subjects themselves. This might create a “therapeutic misconception,” in which study subjects mistakenly believe that their participation implies that substantive benefit is likely [1]. The therapeutic misconception might persist among the majority of subjects despite even rigorous efforts to obtain informed consent [2]. This misconception likely persists because the distinction between clinical practice and research is blurred, especially in research designed to evaluate the efficacy of a therapy. The goals of clinical medicine and research are inexorably at odds with one another. As mentioned in *The Belmont Report*, while the purpose of clinical medicine is to provide diagnosis and treatment, the purpose of research is to test a hypothesis [3]. Thus, an *a priori* responsibility of clinical researchers enrolling patients as subjects is to dispel this misconception by informing them about the fundamentally different goals of clinicians and researchers.

Although clinical trials are not always designed to benefit study subjects, health care professionals (and clinical researchers) have an obligation to future patients. Physicians arguably have the responsibility to maximize the well-being of not only their patients, but also society at large. However, there is a fundamental intimacy to the doctor-patient relationship that is not easily transcended by larger societal obligations and demands. And clinical trials are distinct in that they necessarily encroach on the primacy of the physician-patient relationship; in essence, patients become subjects, so patients and families are no longer the center of care.

Despite these shortcomings, there might be many legitimate reasons why a physician might suggest that a patient participate in a clinical trial. Patients facing potentially imminent death might want to participate in clinical research because they view any additional relative risk as minimal. Miller and Brody argue that clinical trials can be ethical under two conditions: when there are only slight risks of study participation compared to standard practice (prefaced upon clinical equipoise), or if they offer the (remote) possibility of therapeutic benefit for patients who have exhausted all standard therapy other than comfort care [4]. So-called “sacrificial altruists” might even choose to participate in order to advance our collective understanding for future benefit, even if participation could result in direct harm. A commonly reported wish of many patients near the end of life includes the desire to help future patients [5]. One can convincingly argue that, rather than needing protection from herself, Janet similarly deserves to be

considered as a trial participant. However, should physicians always be obliged to disclose information about clinical trials to their patients?

### **Shared Decision Making**

Hippocrates, long regarded as the father of modern clinical medicine, once encouraged physicians to “[conceal] most things from the patient while attending to [him]; [to] give necessary orders with cheerfulness and serenity...revealing nothing of the patient’s future or present condition” [6]. Until recently, physicians routinely assumed this kind of paternalistic role, using their professional expertise to make decisions they judged to be in the best interests of their patients. In today’s lexicon, however, “paternalism” has become more of a moniker for arrogance and authoritarianism [7]. More collaborative approaches to maintaining patient-physician relationships are now considered appropriate. Roeland and colleagues [7] describe Kon’s concept of the “shared decision making continuum” (with “physician-driven care” at one extreme and “patient-driven care” at the other [8]), in which the physician’s role is “determining the appropriate level of patient autonomy when addressing treatment decisions” [9]. We consider this a useful approach for considering this case.

Shared decision making requires physicians to consider a spectrum of information [sharing](#). Physicians do not generally want to share irrelevant or unhelpful information with patients, but they do want to invite patients to help them assess what, according to their values and ways of seeing the world, would constitute relevant and helpful information. There are several exceptions to informed consent that allow physicians to withhold information from their patients. Physicians [might invoke](#) the principle of [therapeutic privilege](#) (or therapeutic exception) in extraordinary circumstances when they believe that withholding information offers substantive therapeutic benefit, such as preventing acute emotional distress that compromises health [10]. Furthermore, even if disclosure would not cause direct harm, physicians are not compelled to recommend anything they do not believe confers medical benefit or is not relevant to the decision at hand. Shared decision making works best when physicians have excellent interpersonal communication skills and a high level of emotional intelligence, as a physician must titrate and distill information according to his or her interpretation of responses from patients about their values and goals of care.

By withholding information from Janet, Dr. Haveford seems to be acting appropriately. While it is not clear if Janet would suffer direct harm from the disclosure of clinical trial options, Dr. Haveford does not believe that clinical trials will offer a therapeutic benefit (nor is that how trial candidacy is established). In fact, he is concerned that a clinical trial and aggressive treatment could actually harm Janet, either directly or indirectly. Dr. Haveford has established a rapport with her and believes that, while she wants to remain informed, she does not want to be burdened with choices and would rather delegate her responsibility to make certain medical decisions to entrusted clinicians. Dr.



Haveford is acting in accordance with his best impression of Janet's wishes regarding how much information she receives and how medical decisions are made. Since such decision-making practices would vary depending on a patient's values, understanding patient values is crucial in determining how much information to disclose. Of course, we create a tautology if we are to require a clinician to *know* exactly how a patient would react to information that has yet to be disclosed; as in all aspects of medicine, judgment and experience are critical.

Shared decision making is especially important in end-of-life care, when the consequences of medical decisions become magnified. Under the informed choice model, many patients choose the more aggressive treatment, perhaps because they view anything less as giving up [11]. The idea that one should not give up, but rather fight using any means necessary, is a common belief that has permeated our medical culture. But there is little evidence that such treatment leads to better outcomes. Indeed, a randomized study involving terminal lung cancer patients found that those receiving early palliative care integrated with standard oncologic care survived two months longer, had a better quality of life, and experienced less depression than those who received standard care alone [12]. Shared decision making has been shown to encourage patients to consider less aggressive care [13], which might result in better health outcomes.

Also, as Roeland and colleagues put it,

it has been our observation that, as patients approach death, medical providers frequently defer these [life-or-death] decisions to patients and/or loved ones...hoping that the patient and/or family will say, "No more." However, this unintentionally causes the patient and/or loved ones to feel as if they are "pulling the plug".... [P]atients and/or loved ones want the medical providers to make the decision so they are not responsible for "killing" themselves or a loved one [9].

A physician actively participating in a shared decision-making process can shift some of the emotion-laden responsibility to forego additional medical interventions [away from the patient](#) and thereby make patients feel more comfortable with end-of-life decisions, as Dr. Haveford has done in this case.

### **Disagreements about Patient Care**

How should Isalita, as a medical student, handle her sense that Dr. Haveford is not honoring Janet's wishes? In *The Anatomy of Hope*, Jerome Groopman tells the story of a patient who refused breast cancer treatment against the recommendation of the attending physician [14]. Although she did not tell the attending physician her rationale, she confided in Dr. Groopman, then a resident, who shared her religious faith, that she was refusing treatment because she believed her illness was a "punishment from God"

and that she must accept her fate. Since medical students might spend more time with patients, they can sometimes have additional insight into a patient's values. In such a case, medical trainees should draw upon their primary roles as learners, ask questions of attending physicians, and express their concerns to faculty teachers and mentors, one of whom in this case is Dr. Haveford.

Given their place in the medical hierarchy, it can be difficult for many medical students to confront superiors, particularly when disagreements arise. However, a major tenet of practice-based learning is the need to recognize that the supremacy of the patient's best interest will always supersede seniority or position. While imposed power dynamics are real and mentors might occasionally be dismissive, students are obligated to advocate for their patients. As such, medical students, along with any member of the care team, are entitled and entrusted to be respectful but outspoken in articulating concerns about patient care, which includes having the moral courage to supersede traditional hierarchies when necessary [15]. Much responsibility also lies with the medical institution to foster an environment where honest dialogues can occur without fear of repercussion. In most cases, including this one, such a statement from Isalita will engender a discussion with Dr. Haveford, which may or may not affect his decision in this case, but that will undoubtedly further Isalita's understanding of what it truly means to be entrusted with a patient's life.

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#### **Related in the *AMA Journal of Ethics***

[The Use of Informed Assent in Withholding Cardiopulmonary Resuscitation in the ICU](#), July 2012

[Why Not a Slow Code?](#) October 2012

[Selective Paternalism](#), July 2012

[Withholding Information from an Anxiety-Prone Patient?](#) March 2015

[Invoking Therapeutic Privilege](#), February 2004

[The AMA Code of Medical Ethics' Opinions Relevant to Patient- and Family-Centered Care](#), January 2016

The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental.

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# American Medical Association Journal of Ethics

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## ETHICS CASE

### What's the Role of Autonomy in Patient- and Family-Centered Care When Patients and Family Members Don't Agree?

Commentary by Laura Sedig, MD

Dave's health is on the decline. Despite surgery, chemotherapy, radiation, and hormonal treatments, his prostate cancer has metastasized to his bones. When he's been in and out of the hospital for four months or visiting clinic for lab tests and treatments, he's often accompanied by his wife Jessica and one or both of his two children, Christine and Alex. Dave's family has remained optimistic, confident, and encouraging; they fully expected him to pursue aggressive treatment. Dave's physicians, however, now want to transition his care and incorporate hospice and palliative approaches to managing his illness.

The palliative care physician, Dr. Barelle, sits down alone with Dave to discuss his end-of-life wishes. Dave insists on pursuing aggressive acute care for his prostate cancer, but he also seems exhausted. As Dr. Barelle continues to describe what aggressive acute care would entail over the next months and begins to probe deeper into Dave's goals of care, Dave slowly confesses that he worries about aggressive treatment, states that it isn't what he wants, and also says, "I'm not the hero type." He goes on to express that he particularly values his independence and that he fears pain, suffering, impending loss of functioning, and loss of his autonomy. He finally admits that aggressive acute care seems to him to be excessive and futile at this point but that he doesn't want to let his family down by not "fighting." He fears that his family thinks of hospice and palliative care as capitulating and "giving up."

Dr. Barelle has suspected that Dave's wishes were diverging from his family's, and she wonders how to acknowledge this and how to advocate on Dave's behalf in ways that won't be divisive. What should she do? Should she downplay the potential of aggressive care to better persuade the family to respect the patient's wishes?

## Commentary

In order to best care for Dave, Dr. Barelle must consider how to respect both his autonomy and the role of his well-intentioned and loving family in his care. She must also remain an advocate for his stated wishes without being paternalistic about his choice to follow his family's wishes. Furthermore, Dr. Barelle is in a challenging position as she is newly involved in Dave's care and does not have a long-standing relationship to serve as a foundation for these difficult conversations. So, we might wonder at this

point, what is the appropriate nature and scope of autonomy and the role of family members in a case like Dave's?

### **Patient Autonomy and Informed Consent**

Expressing respect for patients' autonomy means acknowledging that patients who have decision-making capacity have the right to make decisions regarding their care, even when their decisions contradict their clinicians' recommendations [1]. Beauchamp and Childress remind us that autonomy requires both "liberty (independence from controlling influences) and agency (capacity for intentional action)" [2] and that liberty is undermined by coercion, persuasion, and manipulation [1]. The ideal of "informed consent" is a hallmark of Western medical ethics that came about following the horrors recounted in the Nuremberg trials and was codified in American law through *Canterbury v. Spence* in 1972 [3]. It requires physicians to respect patients' autonomy by giving them the information needed to understand the risks and benefits of a proposed intervention, as well as the reasonable alternatives (including no intervention), so that they may make independent decisions.

A patient's independence is traditionally the highest priority in American bioethics [1]. American bioethics circumscribes the role of others who might influence the patient to make a choice that does not put his own wishes or best interests first. Although this emphasis is intended to prevent patients from being coerced, especially by medical professionals, it ignores that a patient is part of a family. Patients often wish to take their family members' opinions into account when making medical decisions, as they would with many other important decisions. Respecting patient autonomy thus includes respecting both how patients wish to make a decision and the decision made, even if the decision is to allow their family's desires to supersede their own [4, 5].

### **Influence within Families**

Reminders to respect a patient's liberty are generally directed toward clinicians, but family members [can](#) certainly coerce, persuade, or manipulate a patient. Agency, however, allows a patient to consider how a decision he or she makes might affect his or her family members. It is both common and socially acceptable for a patient to consult family members in order to aid in decision making. Focusing on the strict definition of autonomy and failing to recognize an individual as part of a family leads to an incomplete understanding of decision making for informed consent [2].

Despite the fact that most families offer suggestions with the best intentions, there are situations in which family members become unduly persuasive, manipulative, or coercive. For example, if family members are threatening to remove support, financial or otherwise, for patients if they do not make the decision desired by the family, the family would be manipulating the patient. Therefore, clinicians must be mindful of the potential for this dynamic and advocate for the patient to ensure that he or she feels free to make

an independent decision.

In this case, Dave has elected to make his decision based on the wishes of his family. He and his family have been presented with the relevant information to consider, and Dave appears to be making that decision without evidence of coercion by his family. Dave's decision therefore appears to be consistent with Beauchamp and Childress's description of the five components essential to informed consent: competence, disclosure, understanding, voluntariness, and consent [1]. In Dave's case, his competence is not in question. Dr. Barelle has disclosed what aggressive care and comfort care would be like and Dave appears to understand the differences between treatment options. He is making his decision without undue influence from his family or clinician, and he has given his consent to proceed with aggressive treatment.

Despite giving informed consent, he continues to struggle with the conflict between his desire to avoid further aggressive therapy and his desire not to cause additional pain to his family by refusing treatment that they wish him to undergo in hopes of prolonging his life. His conflict may cause discomfort for Dave and Dr. Barelle, but his decision is voluntary. Although it might be challenging to accept that Dave is choosing a course of treatment with a high chance of suffering for little chance of benefit, it is a reasonable decision to make. Some patients decide to do everything possible to prolong their lives, even if the treatment is harsh. The decision is acceptable as long as it is autonomous and the patient is aware of the risks and benefits of treatment.

If Dave's family were exercising undue influence, Dr. Barelle would be obligated to identify that as unacceptable and discuss it with Dave. In the case of undue influence from family members, Dr. Barelle would be obligated to follow the patient's wishes after discussion with his or her family.

### **Nourishing Family Relationships during High-Stakes Deliberations at the End-of-Life**

There is research about how patients and family members think medical decisions should be made and which values they consider important. This information could help inform Dr. Barelle as she counsels Dave in hopes of achieving a treatment plan in accordance with Dave's stated wishes while maintaining his close family relationships. For example, Schäfer et al. [6] surveyed patients and family members about who should receive medical information and make medical decisions and how disagreements should be resolved. Ninety-three percent of respondents felt that both patients and family members should receive medical information; 70 percent of patients felt that family members should have a role in decision making, but only 54 percent of family members felt that they should. Most respondents (78 percent) thought it was important for patients, their families, and their physicians to resolve disagreements jointly. These findings suggest that Dave might be taking his family's wishes into account more than his family would want or expect, and that his family might wish to resolve the conflict

with a discussion involving Dave and Dr. Barelle.

Schäfer et al. [6] also asked patients and family members to rank their values at the end of their or their loved one's life. Both patients and family members ranked family, partner, children, and health in the top four, although in a different order. Freedom and independence were ranked seventh and eighth by patients and eighth and ninth by family members, with long life ranked eleventh by both groups. These results suggest that the values of patients and their family members are fairly closely aligned. Therefore, facilitating a discussion about Dave's underlying values might be a strategy for Dr. Barrelle to generate concordance between him and his family.

Knowing that patients might care more about incorporating their family's wishes into their decision making than family members themselves do might be helpful to physicians wanting to encourage Dave to discuss his desires with his family. Dr. Barelle can remind Dave that his family might be more open to his desired treatment option than he thinks. Even if their initial wishes are incongruent, patients and families usually have the same underlying values. This provides a basis for further discussion about overarching hopes for treatment outcomes and might help Dave and his family agree about how to approach his care at this stage of illness. Even if they do not agree, they might have a better understanding of each other's perspectives.

Decisions made in situations of high stress, such as treatment decisions when there is little hope of substantial benefit, are difficult for all patients, families, and physicians. It is even more difficult when the physician's relationships with the patient and the patient's family have not had time to develop. A new addition to the patient's care team, such as Dr. Barelle, must work to build her relationships with the patient and the patient's family for them to trust her and her recommendations. Additionally, when a patient's care is divided among multiple clinicians, it is ideal for all of the clinicians to discuss the case among themselves to minimize confusion for the patient and family. Having such a discussion does not mean that the clinicians come to a decision for the patient, but rather that they all agree on the available options and the potential risks and benefits of each in order to present a consistent interpretation of the current situation and the reasonable next steps. It is important for Dr. Barelle and Dave's oncologist to confer so that they are both presenting the same options to Dave and his family.

### **Resolution**

The physician-patient relationship is a fiduciary relationship in which the physician is obligated to act in the patient's interests, with respect for the patient's autonomy. Physicians are also bound by patient-physician confidentiality. When an autonomous patient's stated wishes and actions are not aligned, the physician [must](#) both respect the patient's decision and keep his wishes confidential if he has asked her not to disclose them. However, Dr. Barelle can demonstrate her support for Dave by continuing to

advocate for his personal wishes, even if that advocacy is done primarily at appointments in which his family is not present. Dr. Barelle should discuss with Dave precisely which pieces of information he is comfortable having her disclose to his family so that she does not break physician-patient confidentiality in her attempts to advocate on his behalf. If he is comfortable with greater transparency, Dr. Barelle should discuss his values and hopes, as well as his family's values and hopes for him, as a foundation for setting care goals—prolonging life or minimizing suffering, for example—during another appointment at which a family member is present.

Prior to a conversation with Dave's family regarding the risks and benefits of pursuing aggressive therapy (or not) and goals and values, Dr. Barelle should work with Dave on how medical information and his values should best be presented to his family. He can provide insight into how his family would best understand the medical information, and they can discuss how to help his family understand his wish not to pursue aggressive therapy, even if he refuses to tell them directly. It is not acceptable for Dr. Barelle to downplay one option with the goal of persuading Dave's family to choose a different option without his express permission. However, after Dr. Barelle has ensured that Dave and his family all have realistic expectations for pursuing—or not pursuing—aggressive therapy and has held a discussion regarding their goals for the end of Dave's life, Dave and his family might be better able to come to a resolution with regard to his treatment. A deeper conversation with Dave and his family about broad goals and values at the end of his life—especially independence—might help them to find more common ground or some level of comfort agreeing to disagree.

A best result of this conversation would be that Dave and his family come to an agreement with regard to his future treatment. It could also happen that his family continues to disagree with his decision but supports him as an independent decision maker. Alternatively, Dave's family might continue to disagree with his wishes and Dave might continue to defer to his family, which is still acceptable provided these conversations have not demonstrated evidence of coercion, undue influence, or manipulation. Unfortunately, Dave and his family might continue to disagree, with growing tension in their relationship due to this disagreement. In this situation, enlisting social work and chaplaincy to help with [family dynamics](#) could be a good strategy for mitigating this tension and thus would likely be in everyone's best interest.

Whatever Dave's ultimate decision, Dr. Barelle will have respected Dave's autonomy and provided him and his family with all of the information needed for Dave to give informed consent for the next phase of care. She will also have laid the groundwork for continued discussions as Dave's cancer progresses and more decisions must be made.



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## Related in the *AMA Journal of Ethics*

[Who Decides, Patient or Family?](#) August 2007

[Family-Centered Decision Making](#), June 2008

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[Should Children be Asked to be Bone Marrow Donors for Siblings?](#) January 2016

[Family Disagreement over Organ Donation](#), September 2005

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## ETHICS CASE

### Should Children be Asked to be Bone Marrow Donors for Siblings?

Commentary by Katrina Ann Williamson and Christian J. Vercler, MD, MA

Fifteen-year-old Mandy has acute myeloid leukemia (AML) and needs a bone marrow transplant. Mandy's parents and younger sister Jessica all undergo testing to determine whether any of them is a prospective donor. Jessica, who is eight, is found to be a match, and Mandy and her family are overjoyed that she will be able to have the transplant.

Jessica's parents explain to her that she is able to help her sister by having an operation to take part of the marrow inside her bones and give it to her sister, who, as Jessica knows, is critically ill. Jessica seems excited about the possibility of helping her older sister, so the parents provide initial consent for her to do so.

Jessica's enthusiasm remains when she and her parents meet with Dr. Malone, the bone marrow transplant physician, and his team. Jessica asks some questions, and Dr. Malone assures her that her bones and blood will make more marrow to replace what is removed. Then Dr. Malone asks Jessica to stay to talk with him by herself. During this conversation, it becomes clear to him that she has not fully understood what the donation would entail. She seems concerned and anxious as she asks him whether it will hurt and about what could happen to her if she has the procedure, and she is visibly frightened about having to be put to sleep.

Dr. Malone is concerned that Jessica may be unduly influenced by her parents' and sister's expectations that she will donate. When he talks with her parents, however, they say they know Jessica well and that her sister's health is more important to her than the immediate pain of the procedure. They explain that they, along with Mandy, will give Jessica much support and attention, and they insist that she will feel privileged and glad to have been able to help her sister for the rest of her life.

## Commentary

A central question in this case is the ethical permissibility of using Jessica as a bone marrow donor in light of her seeming reticence and fear regarding anesthesia and pain. Some might prioritize the physician's duty to respect patient autonomy. In this era of patient-centered care, a case like Jessica's sparks a great deal of controversy because at first glance it is unclear whether, because of her age and familial pressure, she is capable of assenting voluntarily to an invasive procedure from which she derives no medical benefit.

Whenever possible, a child's opinions concerning the interventions to be performed on his or her body should be [carefully considered](#). Although minors cannot technically consent to medical interventions—parents do so on behalf of their children—we honor their opinions in the concept of, and in seeking, assent. We generally accept the moral authority of a child's parents, except in cases of abuse or neglect. Parents are uniquely situated to both know and protect the child's best interests, and therefore, the reasoning typically goes, they will only permit the child to undergo a potentially painful procedure when the health benefits of that procedure outweigh the risks.

When the benefit of treatment is clear, we tend to have fewer ethical qualms about treating a child without her assent because it is in her best interest. However, for [a procedure that confers no direct medical benefit to the child](#), respecting a child's autonomy—obtaining a child's assent or appropriately regarding his or her dissent or refusal—is generally thought to be of paramount ethical importance. How should assent, dissent, or refusal in a case of bone marrow donation be weighed in ethical decision making concerning a [child donor](#)? Decision makers are burdened with great responsibility: their choice will have life-and-death consequences for another vulnerable child. Which criteria ought to be used to determine whether and when it's ethical to expect this level of responsibility from a child like Jessica?

The American Academy of Pediatrics Committee on Bioethics (AAPCOB) deems the use of a child bone marrow donor ethically appropriate when five conditions are met [1]. Jessica's case easily meets three of the five criteria. First, no adult matches are available to donate to the child needing the transplant. Second, the bone marrow transplant must confer a reasonable benefit to the recipient, which can be assumed in this case. Depending on the stage of AML, a bone marrow transplant confers between 30 and 65 percent chance of survival [2]. And third, a strong personal relationship must exist between the donor and the recipient. It seems in this case that Jessica and Mandy have a normally tight sisterly bond, but open ethical questions can certainly remain about how the relationship is assessed and by whom.

The fourth condition requires consideration of the risks and benefits of donation. Medical, emotional, and psychological risk to the child donor must be minimal and reasonable in comparison to the benefit gained by the donor and recipient [1]. Bone marrow harvesting, even in children, is considered safe with only slight risk [2]. The general anesthesia, as well as the harvesting procedure itself, however, can have adverse effects. In a small number of donors, harvesting causes nerve, bone, and tissue damage [2]. Rare potential morbidities include pulmonary embolism, sickle cell crisis, and others [2]. And though mortality is quite uncommon—less than one in ten thousand [2]—it is not zero. More likely, though, the physical consequences for Jessica would be limited to pain and days required for recovery. However, possible psychological

sequelae—such as fear and posttraumatic stress [3]—pose additional moral concerns that are not easy to weigh. The physical and psychological risks cannot be trivialized. Any harms that could result from the procedure might adversely affect a previously healthy child. The benefits of harvesting Jessica’s marrow for both Mandy and Jessica must justify the danger and pain of the procedure for Jessica. This is where taking a patient- and family-centered approach could be helpful. Mandy and Jessica exist within the tightly woven social fabric of their family, and so the role played by family dynamics in their lives deserves consideration. It’s not clear, however, *how* to consider those dynamics; we don’t know, for example, which relationships are close and which are strained, and even if we did, it would not be clear how our judgments about those relationships should be weighed in deciding whether and when it is just to ask Jessica to be a donor for Mandy.

It’s probably safe to assume that Mandy would gain tremendous health benefit from Jessica’s bone marrow donation, which offers her the best, and perhaps the only, reasonable chance for survival. If Jessica were not to donate her bone marrow, Mandy would be unlikely to receive a transplant at all, because donors unrelated to the recipient are hard to find [2]. While it’s not clear whether Jessica’s marrow donation will keep Mandy alive (or for how long), it does seem reasonable to foresee that Jessica’s refusal to donate marrow would likely mean that Mandy’s death is imminent.

To more fully understand the benefits Jessica would gain by donating, we must understand the intimate connections between Jessica’s health and happiness and her family’s. Mandy’s deterioration and subsequent death would, presumably, have serious negative emotional short- and long-term consequences for Jessica. Some would be a direct result of experiencing sibling loss; the lifelong bond shared by two siblings is often crucial to a child’s social and personal development [4]. Some studies suggest that the loss of a sibling in childhood can adversely alter personality; hinder social development; and even lead to outcomes, such as fewer years of schooling, with negative impacts on adult life [4, 5]. Donation benefits Jessica by giving her the opportunity to grow up with Mandy and deepen their sibling bond. Donating could also shield her from a potential repercussion of parental grief—the parents’ diminished abilities to care for a surviving child [6]. Mandy’s death thus could undermine the stability and support Jessica’s parents presently provide.

As her parents have intuited, Jessica could benefit not just from the consequences of her sister’s improved health but also from the very act of donating. Devotion to family is often considered “a source of deep meaning and value in our lives” [7]. A sibling donor fulfills and exceeds his or her familial obligation to care for a sibling. Donating may also bring one a sense of personal satisfaction and accomplishment [8]. One study found that bone marrow donors were “proud that they had done something special and unique...that they had lived up to their own ideals and self-values” [9]. One might reasonably worry that Jessica, at age eight, is too limited in her ability to understand the

magnitude of her gift to experience such feelings after donating. Or, one might worry that Jessica could feel sacrificed or used as a mere means of preserving her sister. However, by donating, Jessica could feel that she's heroic. The gratitude and affection her parents and sibling would shower on her might allow her to feel a sense of personal satisfaction and accomplishment similar to that reported in the aforementioned study. If she decided against donating, Jessica might later feel she had failed to meet familial obligations. She could be vulnerable to experiencing extreme guilt and remorse, especially when Mandy dies.

The fifth condition set by the AAPCB—parent consent and patient assent—bring us back to the original ethical dilemma in Jessica's case [1]. If Jessica has been influenced too forcefully by her parents, her assent may simply reflect her capitulation to her parents' control over her life, her powerlessness to resist her parents' authority, or her desire to please them. Is it possible to determine whether her assent is voluntary, and is it ethically permissible to move forward with the bone marrow harvest despite her concerns and fears? One possible strategy for navigating a case like this one would be to appoint an independent adult advocate to meet with Jessica alone and investigate her concerns and fears and then speak on her behalf. Some institutions already make standard practice of consulting [independent advocates](#). Children's Mercy Hospital in Kansas City, for instance, created a Donor Advocacy Program [10]. Young sibling donors meet with both a general pediatrician and a child life professional—both are independent of the transplant team. The advocates' roles are to help inform child donors and aid them in communicating their feelings about the donation process. Donor advocates can help to avoid the pitfall of overemphasizing Jessica's concerns and fears about pain and discomfort, which could be as devastating as the pitfall of ignoring, neglecting, or underestimating her concerns and fears.

Fundamentally, the ethical permissibility of using Jessica as a bone marrow donor turns on whether and how her personhood is valued and respected. The philosopher Immanuel Kant expressed this general idea by suggesting that a person should never be used *merely* as a *means* to an end but must be treated as an end—that is, as valuable—in him- or herself [11]. Jessica *is* the means to her sister's cure and so *prima facie* it seems that her personhood is being violated. But the overall result of achieving Mandy's cure leads to the well-being of her entire family. Since Jessica is an integral part of her family, her ability to thrive comes through the contributions every member makes to the familial unit. As part of her family, then, Jessica is not *merely* a means to an end and so her personhood is respected in the Kantian sense. A patient- and family-centered approach to understanding this decision helps to interrogate the sources of our most important values. Of course, it is imperative that Jessica's concerns about pain and fear of anesthesia should be directly addressed. But addressing them does not mean assuming they outweigh the consequences of not donating.

Dr. Malone should attempt to better inform and prepare Jessica regarding what is to occur during her procedure. He might even be advised to bring in a second physician or a child life specialist to help further Jessica's understanding and validate her feelings. Jessica's resulting level of understanding, however, should not necessarily guide Dr. Malone's and Jessica's and Mandy's parents' collaborative decision to allow the donation. In this case, not allowing Jessica to donate could very likely worsen her future well-being and development. At eight years old, Jessica cannot be expected to fully comprehend the dire consequences that a decision not to donate would have on herself and those around her. Basing such a critical decision on Jessica's emotions or her limited comprehension could be far less ethically advisable than proceeding with a less than clearly autonomous assent. Protecting Jessica, ultimately, comes down to ensuring that potentially harmful physical and psychological effects of the procedure are minimized and that her parents and caregivers respond to her fears and anxieties with compassion. One way to achieve this is by providing support, including counseling, for Jessica and her family and by making Jessica's parents aware of what donors in Jessica's position most often experience.

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# American Medical Association Journal of Ethics

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## MEDICAL EDUCATION

### Teaching Patient- and Family-Centered Care: Integrating Shared Humanity into Medical Education Curricula

Kelly Parent, Kori Jones, MEd, Lauren Phillips, Jennifer N. Stojan, MD, and Joseph B. House, MD

In the aftermath of the Flexner Report of 1910, American medical education emphasized scientific knowledge over communication and empathy [1]. However with the “information age” propelling rapid scientific advancement, creating an overwhelming abundance of information, and democratizing the availability of medical information (though not necessarily medical knowledge) to anyone with Internet access, medical education has been thrust into a new era that emphasizes empathy, humanity, communication, and partnership with patients and families. As a result, medical schools are revising their curricula to integrate principles of [patient- and family-centered care](#) (PFCC) and to emphasize the importance of communication and how physicians can help patients and families translate information into helpful, care-oriented knowledge during clinical encounters. In the words of American physician Francis Peabody (1881-1927), “One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient” [2]. The addition of PFCC content to medical school curricula is poised to bring caring and humanity into the education of our future clinicians.

#### The Case for Patient- and Family-Centered Care

The Institute for Patient- and Family-Centered Care defines PFCC as an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care professionals, patients, and families [3]. Families are included in this definition of health care relationships because they can be important sources of care and support for patients.

In 2001, the Institute of Medicine report *Crossing the Quality Chasm: A New Health System for the 21st Century* made patient-centeredness one of “the aims for improvement” for the health care system, arguing that patient and family engagement and partnerships result in higher patient satisfaction, improved clinical outcomes, and reduced errors [4]. Almost a decade later, the Lucian Leape Institute Roundtable on Reforming Medical Education report, *Unmet Needs: Teaching Physicians to Provide Safe Patient Care*, urged medical educators to place more emphasis on teaching systems, teamwork, and patient and family engagement to promote safe care practices [5]. Furthermore, following passage of the Affordable Care Act of 2010, the Center for Medicare and Medicaid



Services (CMS) aligned its priorities with PFCC, investing in patient safety by tying reimbursement to patient (and family) satisfaction, patient outcomes, and quality and safety Physician Quality Reporting System (PQRS) data [6].

### **The Need for Curricular Redevelopment—PFCC in Medical Education at the University of Michigan Medical School**

To keep current with national standards, as well as culture shifts in health care around patient and family engagement and technology usage, the University of Michigan Medical School (UMMS) implemented a major curriculum revision, which included the incorporation of PFCC concepts. Co-authors of this paper Jennifer Stojan and Joseph House have been intimately involved in the revisions. To accomplish this goal, UMMS engaged co-authors Kelly Parent and Kori Jones from the University of Michigan Health System's Department of Patient- and Family-Centered Care and its volunteer patient-family advisors (VPFAs) to develop and implement coursework for medical students that emphasizes PFCC principles in classroom and home settings.

PFCC was incorporated into two courses in the new UMMS curriculum: "Doctoring: Caring for Patients, Families and Communities" (Doctoring), a longitudinal course that includes patient-student partnerships and home visits to help lay the foundation for thoughtful and skilled clinical practice, and "Initial Clinical Experience" (ICE), a longitudinal clinical experience course organized around three aspects of health care—patients, teams, and systems. The goal in each of these courses is to improve communication skills of both patients and the health care team, thereby improving the care of the patients within the health care system and recognizing the value of partnering with patients and family members.

### **Beliefs of Incoming UMMS First-Year Medical Students**

Prior to the PFCC orientation, an anonymous online survey was sent to the first-year UMMS medical students; 127 out of 170 (75 percent) responded assessing their beliefs about the value of patient and family engagement and participation. Students were asked three PFCC-related questions (see figures 1–3). The data indicated that a majority of new UMMS students believe that the needs and ideals of the patient and family, as well as their participation in care planning and decision making, should be central to physician practice; however, a significant number of students entering medical school either were unsure whether, or did not believe that, family members should be part of the care team (40.9 percent) or welcomed to participate in care (37 percent). These findings indicate that if we expect students to embrace patients and family members as part of the care team, we must engage patients and families as educators with theoretical learning, learning through story, facilitated discussion, and personal reflection beginning the first week of medical school and continuing throughout all phases of medical training.

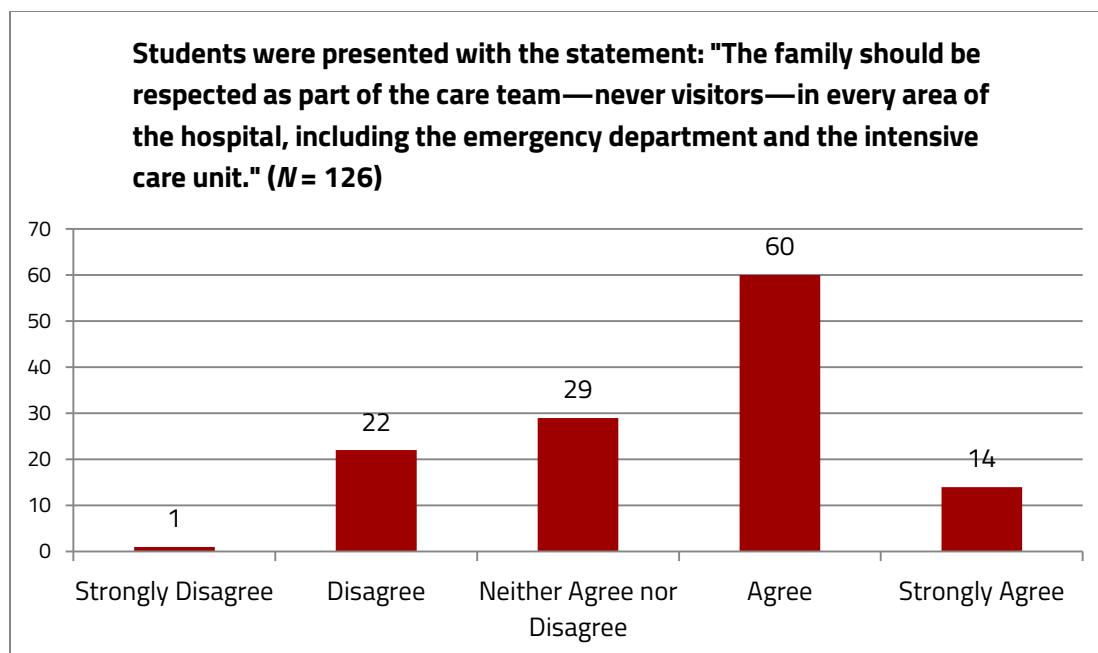


Figure 1. Incoming UMMS medical students' responses to a survey question about respecting family presence.

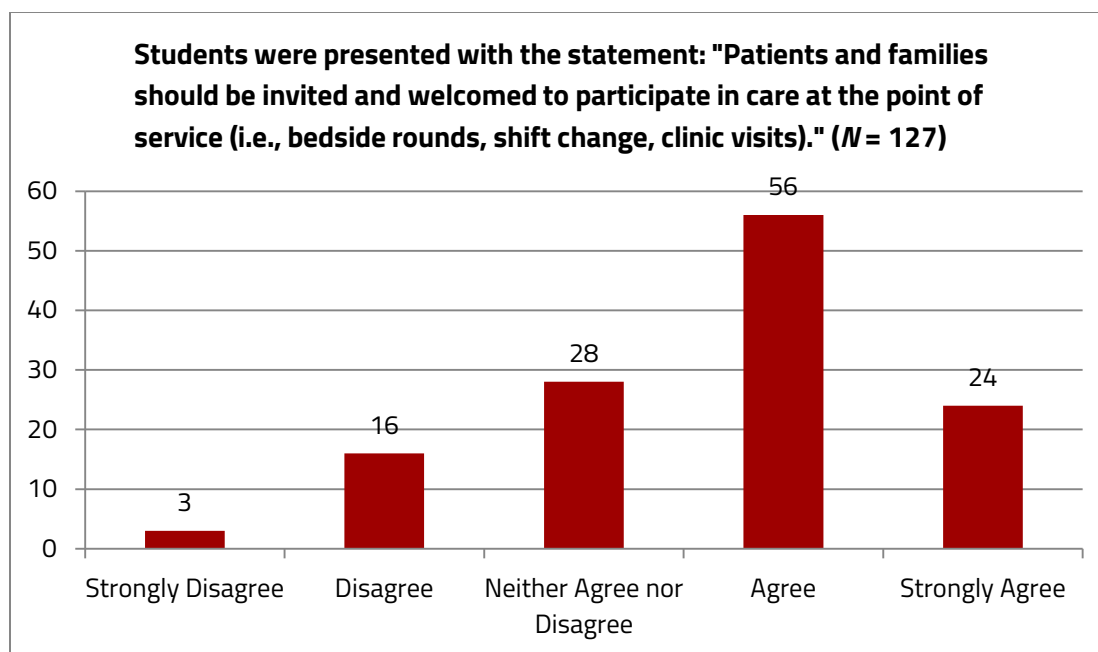


Figure 2. Incoming UMMS medical students' responses to a survey question about recognizing the role of the patient and family as health care team members.

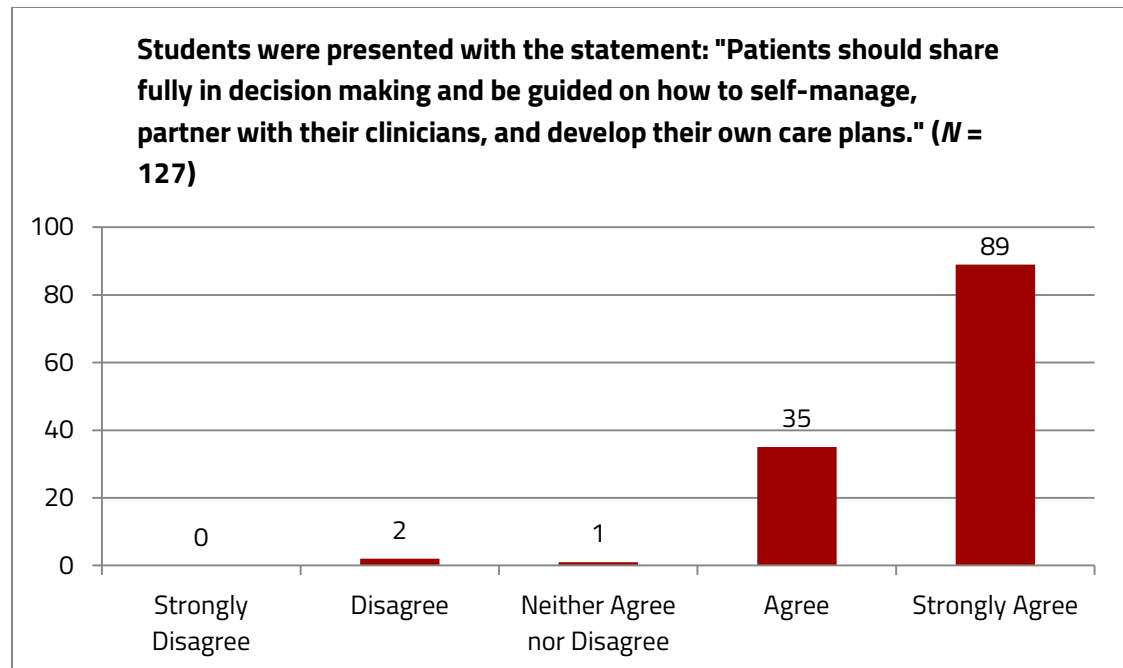


Figure 3. Incoming UMMS medical students' responses to a survey question about welcoming the participation of patients' families in medical decision making and self-management.

### **Input from Patients, Family Members, and Current Students in Developing PFCC Courses**

Department of PFCC staff and VPFA served multiple roles in curriculum design, development, and implementation. For Doctoring, PFCC staff helped to recruit VPFA who could serve as meaningful mentors to medical students and as patient-family panelists whose personal stories would illustrate lessons on communication, health disparities, stigma, and social and cultural identities. PFCC staff and VPFA collaborated with ICE course faculty to create a four-hour orientation consisting of an overview of PFCC; a panel representing the perspectives of four patients and family members and one surgeon; videos emphasizing empathy, patient safety, and PFCC point-of-care interactions; and VPFA-facilitated small group discussions encouraging students to reflect upon all elements of the orientation. To create this curriculum, PFCC staff solicited VPFA input on topics to be included. Suggestions encompassed how to listen, how to communicate both factual and emotional information, how to engage patient and family participation, and how to address difficult situations and escalating behaviors. VPFA also shared ideas for teaching methods: storytelling, personal coaching, small-group discussion, simulation training, case studies, shadowing patients and families, and interactive exercises teaching how to identify words that are understandable and inclusive.

Medical students were also engaged in the curriculum design process. A focus group of seasoned medical students was convened to better understand a "stereotypical profile"

and mindset of first-year medical students. They were asked what they wished they would have learned about empathy, relationships, and communication as new medical students and what they considered to be effective teaching methods. In response to the fact that as many as 50% of first-year medical students expect to become surgeons and are unclear as to how PFCC principles relate to the practice of surgeons, a surgeon was added to the orientation panel to lay the foundation of a patient- and family-centered surgical culture early in medical education.

### **Teaching Methods**

*Didactic education.* Classroom education serves as the theoretical foundation for the benefits of patient and family presence and partnership at the point-of-care; interpersonal skills and communication and education strategies that promote trust, partnership and self-management; and the identification of opportunities to engage patients and families to enhance quality and safety. Presentations include the sharing of literature reviews and best practice models as well as tips and strategies for “what works,” as told by those who have received care.

*A focus on stories.* VPFA panels provide an important venue to learn through story. In both courses, stories serve as the heart of education given their ability to create human connections and emotionally move and motivate us to action. VPFA panelists address the challenges and burdens of illness and injury, the social complexities and stigma of illness and hospitalization, and the differences between empathetic and sympathetic interactions. Story as a personal motivator was also explored. In the pre-orientation survey, incoming students were asked to anonymously share in writing personal health care stories that affected them in profoundly positive or negative ways. Seventy-eight out of 127 students (61 percent) responded with memorable stories (38 positive and 40 negative), and five students expressed that it was these profound experiences that led them to pursue a career in medicine.

*Patients and families as mentors.* The Doctoring course matches two first-year medical students with a patient mentor who is living with a chronic illness or condition. These patient mentors welcome students into their lives and homes, engaging the students in open and honest dialogue about their illness, health care team, and health care system navigation. This unique opportunity allows students to understand illness and the health care system through the “patient’s eyes.”

*VPFAs as discussion facilitators.* After listening to didactic presentations and personal health care experience stories, students have the opportunity to discuss, both in small groups and in writing, how these stories affect us as people and future physicians. PFCC staff selected and trained VPFAs to serve as discussion facilitators. The methodology was to create a space where those who provide care and those who receive care could ask questions, listen to answers, and find a commonality—recognizing that

commonality has the potential to reduce vulnerability and stigma, bridge racial and cultural divides, and build trust and relationships.

### **Potential Challenges**

Although VPFAs as educators provide many benefits, several concerns have been raised as well. Staff and faculty have expressed concern about the time and resources needed to select and train patient and family members to be effective educators. Additionally, concerns have been raised regarding patient and family members pushing their own agendas, anticipated difficulty in maintaining professional boundaries when VPFAs are co-educators one day and patient and family members receiving care the next, and the emotional weight that affecting stories and relationships may have on the emotional development of the student, particularly when there is such limited time for faculty to debrief with students.

Students have also expressed concerns about scheduling and spending time with their patient mentor and being equitably exposed to patient-family panelists who represent a balance of real-life experiences (e.g., well-educated and health care savvy vs. health illiterate and underserved). Efforts to familiarize students with patients and families from diverse cultural, geographical, educational, and socio-economic backgrounds is a constant challenge that requires innovative solutions that build trust and create relationships with underserved communities. A series of home visits in Doctoring is one effort that UMMS has programmed to help respond to these needs.

Finally, to ensure that the principles of PFCC are sustained across the medical education continuum, the curriculum must continue throughout medical school and into residency and fellowship. We must also find a way to set standards of education for attending physicians on these same principles of empathy, communication, and partnership, for without their validation, rising clinicians will not be able to extend classroom learning to the clinical setting.

### **Effect of PFCC Curriculum and Teaching Methods**

While it is too early to determine how PFCC curriculum influences behavior and patient care over time, a preliminary evaluation of medical student impressions of this curriculum has indicated a very favorable response to the PFCC curriculum objectives. More than 94 percent “agreed” or “strongly agreed” that the sessions increased their understanding of: “the challenges of illness/injury for patients and families,” “the benefits of patient and family partnerships at the point of care,” and “the different elements of patient- and family-centered care applied in clinical settings.” In an excerpt of an essay reflecting her impressions of the PFCC curriculum, one UMMS first-year medical student grasped the intended goals of the curriculum:

I sat in the lecture hall donning my short white coat for the first time as we were launched into a talk about something called “Patient- and Family-Centered Care” where we heard about the importance of incorporating family values and beliefs into making medical decisions and partnering ‘with’ patients rather than doing things ‘to and for’ them.... Here we were, first year medical students who had not even begun our basic science courses yet. We could barely pronounce the conditions these patients named, let alone understand them. We had no knowledge of the organ systems affected by their illnesses or the pathology of their diseases. There we were, in the audience, with our white coats on, our only contributions being a set of open ears and a desire to see their experience through their eyes.... And that’s when it hit me—this was why we were there. To see, from the very beginning, that patients can be experts in their own medical experience; to recognize that our personal interactions can be just as important as understanding the medical science behind their illnesses; and to realize that we are not here to be perfect human beings, rather we are here to grow into professionals who can connect with and share in the experience of people who seek our help.

We are assessing students at the end of each term with respect to their skill in communication, patient care, knowledge, and participation surrounding socio-behavioral topics and are exploring the engagement of VPFAs as part of the evaluation process. Revision of curriculum content and teaching methods will be incorporated accordingly.

### **Conclusion**

Our advice to others seeking to create similar programs is this: first, it is important to engage VPFAs who have diverse personal experiences in the health care system and grasp the core principles of PFCC, are unbiased and able to meet first-year medical students where they are, and are willing to attend training to ensure successful panelist storytelling and small-group facilitation. Second, education should be centered on personal stories and reflection, which creates the foundation for empathic relationships. Third, input from both VPFAs and seasoned medical students should be solicited in designing the PFCC curriculum in a way that will reach the students. Fourth, it is valuable to create an assessment and coaching component so that VPFAs can participate in student evaluation of PFCC principles and behaviors. Finally, it must be recognized that [PFCC education](#) is not a “one and done” lecture; it must be continued throughout medical education if true change is to be sustained. Standardization of PFCC-focused processes and expectations among residents, fellows, and attending physicians would ensure that what is being learned in the classroom is being supported and reinforced in patient care.

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## MEDICAL EDUCATION

### Creating Value with the Patient- and Family-Centered Care Methodology and Practice: What Trainees Need to Know, Why, and Strategies for Medical Education

Anthony M. DiGioia III, MD, and Pamela K. Greenhouse, MBA

In 2006, Porter and Teisberg [1] noted that, in keeping with payment models in effect long before the Affordable Care Act of 2010, health care organizations focused on shifting costs, employing financial constraints on insurance coverage to keep patients from seeking health care services elsewhere, and limiting patients' options for accessing health care delivery. Such practices are incentivized in a system in which value is defined differently for patients, insurers, and clinicians and health care organizations, that is, a system in which stakeholders' incentives are not aligned. Porter and Teisberg pointed out that none of these efforts to be competitive created value for patients; instead, they resulted in today's fragmented and costly care delivery system, in which clinical outcomes and patient experiences got much too little attention [2, 3]. A response they suggested was redesigning care delivery models that create value for patients, where *value* is defined as *exceptional experiences and better clinical outcomes at lower cost* [1]. The redesign they proposed was to reform the nature of competition itself by making the competition all about value. So organizations that provide the best patient experiences and the best clinical outcomes at the lowest costs—and rigorously measure and report these results—will succeed. Earlier, in 1999, Pine and Gilmore [4] suggested that engaging customers in a memorable way is critical for creating value. Applied to health care, the idea, they said, is to create a more engaging experience. There is clinical evidence that increased patient and family engagement and partnership in patients' health care experiences are associated with improved clinical outcomes [5].

Neither *value in health care* nor *patient-centered care* (both of which are central tenets of health care reform) are widely taught in medical school curricula. Nor are the concepts that support these tenets, such as engaging with patients in clinician-patient partnerships, evidence-based design and co-design as mechanisms for viewing care through the eyes of patients and families, team-based care, patient activation, and close links between health care organizations' financial and clinical performance. Consequently, medical students don't learn any specific implementation mechanisms for achieving all of these goals. This paper discusses the conceptual and operational components of value and patient-centered care, the importance of introducing them to clinicians-in-training, and ways in which this can be accomplished.

### Is Patient- and Family-Centered Care Ethical?

Conceptually, [patient- and family-centered care](#) (PFCC) is health care that is compassionate and respectful of patients and their families, includes them as partners and collaborators, and acknowledges their dignity. It is also safe, effective, efficient, and equitable [3]. It's hard to imagine an ethical argument against these principles, but one common misconception is that collaborating with patients creates the risk of their making decisions that are detrimental to their health and well-being [6]. But collaboration, by its very nature, means that patients and families don't make decisions in a vacuum, without the input of clinicians; shared decision making is a continuum [7], not an all-or-nothing proposition.

We suggest that clinicians and health care organizations can apply Pine and Gilmore's prescription of creating an exceptional experience of care by partnering with patients and families to redesign care and can do so in a way that increases value by simultaneously improving clinical outcomes and decreasing costs. Experience includes everything that leaves an impression on the patient and family, from their viewpoint—for example, clinical outcomes and care quality, interactions with and among care professionals, transitions in care, the physical environment, safety, and costs. Accordingly, medical education must include (1) coursework that introduces these concepts and (2) a specific implementation mechanism with which to achieve and sustain (over time) focus on patients' experiences and on patient and family-centered care in clinical settings.

### The PFCC M/P

How can we move from PFCC *as concept* to PFCC *as operating system* and operationalize the concept in ways that are measurable? First, we need a way to understand the current state of care delivery, including what patients and families experience along their health care journeys in any setting. Second, we need a mechanism to close gaps between the current and the ideal state (from patients' and families' points of view). The mechanism by which these gaps are closed should create "aha" moments [8] each time it's used, so that its usefulness is apparent. Third, we need a mechanism that not only improves the experience of care but improves outcomes and reduces costs as well. This necessitates that we distinguish carefully between patient *experience* and patient *satisfaction*. A focus on experience, rather than on satisfaction, as we noted in our 2012 paper, "Integrating Patient- and Family-Centered Care with Health Policy: Four Proposed Policy Approaches" [9], is important because it prompts us to look differently at data. For example, patient satisfaction data, while important, "represents, almost without exception, after-the-fact recollections," [10] which makes root causes of problems with patients' experiences difficult to identify and challenging to address. Finally, tools must be easily understood and implemented by clinicians and organizational leaders; sustainable transformation requires a bottom-up-meets-top-down approach.

The PFCC Methodology and Practice (M/P) approach promotes these four things, combining a focus on patients' and families' experiences with tools that can and should

be not only used in clinical settings but also integrated into medical school curricula. Over the last ten years, the PFCC M/P has been [implemented](#) in hundreds of inpatient, outpatient, and pre- and post-hospital and office settings around the world to operationalize the concepts of PFCC [9, 11–20]. It has been implemented in such diverse areas as trauma services, life after weight loss, outpatient mental health, oncology, transplant, home health, diabetes care, and total joint replacement.

### **How the PFCC M/P Works in the Clinical Setting**

Table 1 (below) displays the six steps of the PFCC M/P. The first step is to define (with beginning and end points) the care experience you're setting out to improve in a given organization. This can be as narrow as a physician's office visit in a particular clinic or a particular presurgical test, or as broad as all of a hospital's trauma services from the time paramedics receive a call about an accident or injury all the way through the emergency room, the operating room, an inpatient stay, rehabilitation, home care, and the follow-up visits.

The second step is to form a small (three-to-four-person) strategic group of champions—the guiding council—to initiate and set the stage for these transformation efforts. One member of the guiding council should be a clinician, another should be an administrator (to help remove barriers), and one a coordinator to keep the effort organized.

One of the unique tools of the PFCC M/P—introduced during step 3—is shadowing, which is the direct, real-time observation of patients and families as they go through their health care journey. Trained shadowers (who can be students, interns, members of the care team, volunteers, new employees, and so forth) collect objective and subjective information: where the family members go; with whom they interact and for how long; and patients' and families' impressions, feelings, and reactions. Shadowing training takes less than 30 minutes and shadowing tools are provided to help the shadower take notes and create reports. Direct observation of patients and families as they make their way through the care experience defined in step 1 of table 1 fosters insight into the care experience, which not only helps to accurately and efficiently identify the current state of affairs and opportunities for improvement, but also creates a sense of urgency to drive change. As Tim Brown explains, direct observation creates an emotional connection with the people and processes being observed, which leads to insight and a sense of urgency to improve the care experience [8]. It has been our experience with many medical students that shadowing and observing patients' and families' experiences provides physicians-in-training with unique understanding of the experience of care from the viewpoints of patients and families [21, 22]. Teaching the process of shadowing in medical school can be (1) the initial introduction to the framework of the entire six-step PFCC M/P as well as (2) a valuable tool in its own right for medical students to have the opportunity to view care through the eyes of patients and families in a way that creates “aha” moments [8, 22].

At step 4, high-performance improvement teams composed of clinicians, managers, and leaders—called PFCC working groups and project teams—are organized. PFCC working groups include a representative from every touchpoint (locations to which patients and families go and specialties with which they interact) of the care experience that has been identified through shadowing—from parking attendants to physicians, from nurses to dietitians, from therapists and technicians to schedulers and finance representatives. The creation of these cross-functional and cross-hierarchical improvement teams (i.e., the PFCC working groups) that meet weekly ensures a consistent and permanent opportunity to communicate and collaborate and a forum in which to continually look at the health care experience through the eyes of patients and families. By breaking down silos, this collaboration allows each member of the working group to understand how each part of the care experience fits within the larger care experience from the patient’s and family’s point of view. It is important for students to learn about the importance of team-based care [23]; this step of the PFCC M/P is an example of how to achieve team-based care.

At step 5, these groups write an ideal “story” from the patient’s perspective using the input provided by patients and families during shadowing, and, at step 6, project teams with representatives from every touchpoint launch initiatives to close those experiential gaps identified and prioritized by patients and families.

**Table 1.** The six steps of the PFCC Methodology and Practice [20]

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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**Using the PFCC M/P to Create Fiscal Value**

Currently there is no curriculum for medical students about differences between actual costs, charges, and reimbursement (the latter two [not being directly related](#) to actual

cost) and the need to drive down costs while preserving the quality of patients' experiences and outcomes. The PFCC M/P has recently been expanded into an approach called the Patient Centered Value System, in which shadowing can be used to identify not only the experience of care but also the actual cost of specific types of care such as total joint replacement, heart bypass surgery, chronic diabetes care, and so forth. This goal is accomplished by identifying the major cost drivers (personnel, space, equipment, and consumables) in each segment of care for a given clinical condition during shadowing. Knowing true costs (rather than charges or reimbursements) and their sources, and having the improvement implementation teams already developed within the PFCC M/P, allows clinicians and organizations both to drive costs down while protecting and improving experiences and outcomes and to avoid reducing costs in one segment of care delivery that will only increase costs in another [20]. This is a critical link that has been missing from process improvement until now.

### **Financial Incentives for PFCC?**

Change in health care delivery will be swifter and more widespread if we align clinicians' interests with those of patients and families. Trainees need to know that financial incentives can quicken the pace of adoption of PFCC concepts. As we also suggested in "Integrating Patient- and Family-Centered Care with Health Policy: Four Proposed Policy Approaches" [9], financial incentives could take the form of offering accountable care organizations an additional 10 percent of shared savings if they employ the PFCC M/P. Reallocating a portion of the cost reductions that result from employing the PFCC M/P to population health initiatives, such as wellness and prevention programs, would multiply the achievements of improved experiences and outcomes while further lowering costs.

It is time to implement an operational approach to patient- and family-centered care, and that requires viewing all care through the eyes of patients and families and evaluating performance from a patient-centered perspective. Introducing the concepts as well as the implementation mechanism of patient and family centered care will allow us to transform the health care delivery system to improve experiences and outcomes while decreasing costs—both a logical and an ethical pursuit. Medical school is the place to start. Training medical students in these concepts, teaching them a methodology, and providing the tools with which to achieve them, ensures that from the earliest interactions with patients and families, clinicians practice health care in a patient- and family-centered way.

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#### **Disclosure**

Anthony M. DiGioia discloses an affiliation with GoShadow, LLC.

#### **Related in the *AMA Journal of Ethics***

[Patient- and Family-Centered Care: A Systematic Approach to Better Ethics and Care](#), January 2016

[Patient- and Family-Centered Care: It's Not Just for Pediatrics Anymore](#), January 2016

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## MEDICAL EDUCATION

### Patient- and Family-Centered Care: It's Not Just for Pediatrics Anymore

Aaron M. Clay, RN, and Bridget Parsh, RN, MSN, EdD

Patient- and family-centered care (PFCC) is changing the way hospitals provide patient care, increasing staff satisfaction, decreasing costs, and improving patient outcomes [1, 2]. Although hospitals make unique, organization-specific PFCC principles, all of them tend to endorse similar core values by recognizing the importance of family members' roles in individual patients' health care experience, establishing relationships with and supporting patients and families, and helping patients discover how their own strengths and weaknesses influence their health and health care. When patients' needs are prioritized, they engage in treatment and the treatments are more effective [1-4]. Hospitals where PFCC is part of the organizational culture find not only that patient, family, and staff satisfaction ratings significantly increase, but also that patients' health outcomes improve [2, 5]. Implementation of PFCC is also correlated with a decrease in patients' emergency department visits, faster recovery, and decreased utilization of health care resources [2, 6-7].

PFCC has [become widespread](#) throughout health care [6, 8-12]. The PFCC concepts of *patient-physician collaboration* and *treating the patient as a whole person* are not new. Fifteen years ago, the Institute of Medicine (IOM) semi-annual report, *Crossing the Quality Chasm* [8], included PFCC as an initiative to improve quality in the list of ten rules for redesigning health care [13]. The IOM report emphasized the need to involve patients in their own health care decisions, to better inform patients of treatment options, and to improve access to information [8]. PFCC provides a holistic approach to patient care, including psychological, spiritual, cultural, and emotional considerations that contextualize experiences of illness or injury and go beyond a focus on disease processes only [1].

The term "family-centered" does not remove control from competent patients to make decisions concerning their own health care [11]. Instead, this concept emphasizes that a patient's health care decisions should be contextualized in terms of a patient's broader life experiences. This term also recognizes the role a patient's family members play in extended and at-home care planning and care giving.

As medical care continues to become more collaborative, with a focus on holistic care for patients and their sources of support, principles of PFCC are now commonly taught to medical residents [14, 15]. For example, to be recognized by the Magnet Recognition



Program, developed by the American Nurses Credentialing Center, hospitals must implement family-centered care [16]. No longer just for pediatrics, patient- and family-centered care applies to patients of all ages and can be practiced in any health care setting and at any point in care delivery; the Joint Commission suggestions include providing discharge instructions that meet the patient's needs, informing patients of their rights, and identifying patients' dietary restrictions that affect treatment [1]. Giving patients control, customizing care according to patients' needs and values, and providing information to patients and their loved ones are other IOM recommendations that promote PFCC [8].

Recognizing the importance of patients' loved ones in patients' health care experiences, clinicians try to work with patients and families to ensure their health and well-being in a mutually beneficial relationship [8, 11, 12]. Principles of PFCC include listening to families, facilitating choice, sharing information, and building confidence to participate in health care decision making [2, 11]. By implementing PFCC, clinicians benefit by gathering more information, improving follow-through, making efficient use of professional time, and decreased health care utilization [6, 9, 11].

Based on the latest research and guidelines [1, 4, 10, 14], these strategies for successful patient- and family-centered care are suggested:

1. *Communicate and collaborate.* According to the Institute for Patient and Family Centered Care, the word "family" refers to two or more persons who are related in any way—biologically, legally, or emotionally. The patient defines who represents his or her family and the level of involvement each family member will have. Involve designated family members, or support individuals, in care discussions, making sure they are available for multidisciplinary rounds to discuss concerns, the health care plan, and progress, and encourage them to participate. Patients and family members can provide information missing from medical charts and can recognize and speak up about errors in care delivery [7].
2. *Promote health literacy.* Patients who are—and whose family members are—unaware of potential adverse effects or benefits of medications prescribed have poor compliance [17]. Providing information in terms patients and family members can understand and encouraging families to participate in the care of their loved ones can result in improved patient outcomes [18, 19]. Take time to understand any influences of language, health literacy, or social, educational, or cultural factors on patients or families. Use "teach backs" and "show backs," in which patients or family members restate information provided by clinicians or display newly taught skills to increase understanding and decrease confusion [20]. This practice gives the care team the opportunity to discern and correct errors or misunderstandings [1, 19].
3. *Include the patient and family.* Work toward a professional, respectful relationship with your patients, incorporating their preferences and values in care goals and

plans. Identify and address patient communication needs promptly, such as assistance for family members whose preferred language is not English or who have sensory or communication impairments. Disclose and acknowledge any medical errors promptly, per your facility's policy. When making clinical decisions, consider individual patient values along with possible language barriers, cultural issues, health literacy, and other factors [21, 22].

Prominent organizations including the Institute of Medicine (IOM), the Institute for Patient- and Family-Centered Care (IPFCC), the Institute for Healthcare Improvement (IHI), the American Academy of Pediatrics (AAP), and the American College of Emergency Physicians have endorsed PFCC practices, helped to define PFCC, and illustrated the importance of incorporating patients and their loved ones into health care discussions and decisions [8-12]. PFCC improves quality and safety of care, chronic disease management, and patient satisfaction; reduces hospitalizations and medical errors; and lowers costs [1, 2, 6, 11, 17, 21].

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# American Medical Association Journal of Ethics

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## THE CODE SAYS

### The AMA *Code of Medical Ethics'* Opinions Relevant to Patient- and Family-Centered Care

Danielle Chaet, MS

*This section summarizes content from AMA Code of Ethics opinions.*

#### Therapeutic Privilege

[Opinion 8.12, "Patient Information,"](#) explains that it is a "fundamental ethical requirement that a physician should at all times deal honestly and openly with patients" and that "patients have a right to know their past and present medical status" [1]. [Opinion 8.082, "Withholding Information from Patients,"](#) elaborates that "withholding medical information from patients without their knowledge or consent is ethically unacceptable" [2]. However, when a physician believes that disclosing certain information could be harmful to the patient, the physician may delay disclosure to a more suitable time, provided there is a definite plan for communicating that information to the patient later. According to this opinion, physicians are encouraged to [honor patients' requests](#) not to be informed of certain medical information or to "convey the information to a designated proxy, provided these requests appear to genuinely represent the patient's own wishes" [2].

#### Managing Conflicts among Family Members and Patients

Although [Opinion 10.016, "Pediatric Decision-Making,"](#) generally refers to medical decisions for younger patients, the guidance regarding conflict among family members can be useful in other situations. The opinion states that "when disagreements occur, institutional policies for timely conflict resolution should be followed, including consultation with an ethics committee, pastoral service, or other counseling resource" [3]. Drawing upon the best interest principle—the principle that decisions ought to be based on what's in the best interest (however that's defined) of the patient—is one way to help facilitate decision making.

For conflicts among family members and patients regarding transplantation specifically, [Opinion 2.15, "Transplantation of Organs from Living Donors,"](#) outlines the steps that should be taken to determine if a donor candidate is suitable for the procedure [4]. Because living organ donors are exposed to surgical procedures that pose risks but offer no physical benefits, they require [special safeguards](#) and are not, generally, ethically required to participate in organ donation.

### **Involving Family Members in ICU Decisions**

[Opinion 2.037, “Medical Futility in End-of-Life Care,”](#) outlines a seven-part “due process approach” to assessing medical futility in specific cases:

- (a) Earnest attempts should be made in advance to deliberate over and negotiate prior understandings between patient, proxy, and physician on what constitutes futile care for the patient, and what falls within acceptable limits for the physician, family, and possibly also the institution.
- (b) Joint decision-making should occur between patient or proxy and physician to the maximum extent possible.
- (c) Attempts should be made to negotiate disagreements if they arise, and to reach resolution within all parties’ acceptable limits, with the assistance of consultants as appropriate.
- (d) Involvement of an institutional committee such as the ethics committee should be requested if disagreements are irresolvable.
- (e) If the institutional review supports the patient’s position and the physician remains unpersuaded, transfer of care to another physician within the institution may be arranged.
- (f) If the process supports the physician’s position and the patient/proxy remains unpersuaded, transfer to another institution may be sought and, if done, should be supported by the transferring and receiving institution.
- (g) If transfer is not possible, the intervention need not be offered [5].

These steps can also be used to facilitate involvement of family members in ICU decision making [5].

Opinions [2.22, “Do-Not-Resuscitate Orders”](#) [6], and [2.191, “Advance Care Planning”](#) [7], both discuss benefits of considering various life-sustaining interventions prior to the occurrence of a traumatic incident. Both opinions maintain that patients should do their best to make their wishes known, but, in the absence of that knowledge, a formally designated surrogate decision maker (appointed *before* an event that incapacitates the patient) or next of kin or close family member should make decisions based on [the best interest principle or the substituted judgment standard](#)—the standard by which a surrogate does his or her best to imagine and formulate, as accurately as possible, which decision the patient would make if he or she had capacity to do so.

[Opinion 5.05, “Confidentiality,”](#) states that “the physician should not reveal confidential information without the express consent of the patient, subject to certain exceptions that are ethically justified because of overriding considerations” [8]. Emergency situations are generally considered to be such exceptions—times at which it is ethically appropriate to disclose information to someone, such as a family member or someone

designated by the patient (in cases in which a designee is known), who can make medical decisions for an incapacitated patient.

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# American Medical Association Journal of Ethics

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## STATE OF THE ART AND SCIENCE

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

Michael L. Millenson, Eve Shapiro, Pamela K. Greenhouse, MBA, and Anthony M. DiGioia III, MD

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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# American Medical Association Journal of Ethics

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## MEDICINE AND SOCIETY

### Moving Past Individual and “Pure” Autonomy: The Rise of Family-Centered Patient Care

Lee H. Igel, PhD, and Barron H. Lerner, MD, PhD

Over the past half-century, the central relationship in Western medicine—between patient and physician—has shifted from paternalism, in which the doctor decides what is in the patient’s best interest, to patient-centered care, in which decisions that support an individual patient’s needs, goals, and values are made in partnership. Now, a [family-centered approach](#) is contributing to the emergence of what might be called “post-autonomy” medicine. The goal here is not to restore decision-making power to clinicians; rather, it is to develop a more sophisticated version of self-determination—one that accounts for how autonomy occurs within specific social and cultural contexts. So, what are the merits and drawbacks of autonomy-based thinking in medical decision making today? What are ethically relevant consequences of making patients *and* families participate in this process?

#### Evolving Conceptions of *Autonomy*: From Individualist to Relational

Beginning in the 1970s, following a series of scandals in medicine—such as the revelations of the Nazi medical experiments during the Second World War and the United States Public Health Service’s Tuskegee Syphilis Study—and in the context of other movements toward equality, including civil rights and second-wave feminism, Western medicine began shifting away from paternalism [1, 2]. The long-standing model based on physician authority and passive patient acquiescence gave way to one that put an individual’s right to self-determination front and center. With the [prioritization of autonomy](#)—especially “pure autonomy,” in which the patient’s self-determining judgment prevails [3]—came greater attention to the patient’s and subject’s informed consent and advance directives that sought to ensure that the clinician would follow the patient’s wishes, rather than merely relying on his or her own views about a patient’s best interests. Shared decision making models, which became more prominent in the 1990s [4], have advocated more of a partnership between physician and patient but have not questioned the patient’s primary role in making health care decisions.

More recently, the emphasis on the patient as an individual acting separately from his or her loved ones has been questioned. This shift emerged in the mid-1990s and into the 2000s in the form of *relational autonomy* [5, 6], an outgrowth of the feminist movement’s attempt to meet the challenge of balancing individual choice and action within the push and pull of society. One ethically relevant consequence was a growing emphasis on



family members' input in decision making, based on their intimate knowledge of the patient. This development intertwined medicine and family, two age-old institutions that provide care to loved ones [7].

*Technological and political factors promoting recognition of the important roles of family members.* The transition to a "post-autonomy" medicine is a significant social transformation that can be explained in some measure by health care reform legislation that has alternately favored government-sponsored and privatized programs, with both physicians and patients having abdicated increasing numbers of health care decisions to health care organizations. It can also be explained in part by the associated frustrations over cost of and access to care on the part of physicians, patients, and family members. Finally, the literature about both the changing nature of health care delivery and human decision making [8-10] suggests that the traditional physician-patient relationship has disintegrated and been replaced by a "vast array of complex interrelationships among those who receive, provide, and finance care" [11]. This literature also helps explain growth in reliance on family involvement. In essence, the complexity of the system, with its demands for efficiencies and pooling of expertise, combined with the stresses and strains of understanding medical issues and treatment options, can lead patients to feel overwhelmed and attempt to resolve those feelings by seeking harbor in family input.

Related to this complexity of relationships is the broad dissemination of medical information through the Internet, mobile applications, and, more widely, the media [12]. This democratization of knowledge makes it hard to imagine family members not being involved in the health care decision-making process, in ways that are usually helpful (but occasionally intrusive) [13]. That means decisions about health care, which can be scientifically and emotionally complex to begin with, now require an even greater dependence on the skills of collecting, organizing, analyzing, and communicating information [14]. Relatives and friends can help their loved ones effectively and reliably manage some available literature and information [15].

*Longer life expectancy.* Another factor promoting the growing importance of families in health care decision making is the increase in average life expectancy at birth to 78 years of age in high-income countries [16], partly drawn from the technological ability to stave off certain causes of death for individuals who have access to that technology. This development has contributed to increased implementation of responses to technology, such as advance care planning, do-not-resuscitate (DNR) orders, and the use of health care agents and proxies to make decisions for incapacitated patients. While advance care planning does not always yield the result of patient and family wishes being honored, there is evidence that family involvement and presence in end-of-life care discussions can improve quality of care [17, 18].

*Family involvement as beneficial and desirable.* The fact that family involvement is often the default in advance care planning [19] suggests that the notion of family participation, to some extent, has existed all along. Some might assume that family members have the most regard for the values, wishes, and welfare of the patient. Another closely related assumption is that family members' involvement in the shared decision making process can be helpful, based on the belief that personal knowledge and experience are beneficial when serving as surrogate decision makers on behalf of incapacitated patients [20, 21].

*Shifting medical culture.* There are additional reasons for the growing role of relatives in medical decision making. These include shifts in thinking about: (1) culture and ethnicity, (2) the existing legal climate, and (3) the "best interests" standard.

In recent decades, there has been substantial growth in the use of both hospice and palliative care [21]. Both take a holistic approach to quality of life and continuum of care and encourage the participation of families in clarifying treatment goals, especially at the end of life [22, 23]. And as ethnic diversity has become a defining feature of the United States, the collectivist, family-centered values and perspectives of many different cultural groups have increasingly intersected with Western medicine [24, 25]. *The "family-centered care" that Western medicine regards as something new and different is actually an enduring value in many cultures. It is the norm and a tradition, for example, in [some Asian cultures](#), which place emphasis on strong family bonds and networks [26-28].*

Medical culture seems to be evolving in other ways, too, as suggested by apparently unsettled conceptions about relationships between individual and relational autonomy. Although courts of law have rendered legal decisions with policy implications, they have not often resolved the emotional and moral issues that are associated with—and usually underlie—some of the cases in question. Consider, for example, the 1980s case of Claire Conroy, in which the Supreme Court of New Jersey ruled that artificial feedings, like other life-sustaining treatments, concern the patient's best interests and that shared decision making by physicians and surrogate family members is an inadequate safeguard for an incompetent patient [29]. Given the close relationship between autonomy and decision making across the range of consent and refusal, respect for autonomy may too often be given disproportionate weight relative to other important ethical concepts, such as nonmaleficence, beneficence, and justice [3]. And, despite the prevalence of written directives, power of attorney documents, religious tenets, recorded patterns of prior medical treatment, and other expressions of autonomy-based values in clinical practice, there are questions about the degree to which this information actually expresses a patient's values. As the highly-publicized case of Terry Schiavo showed, conflicts of interest based on family dynamics and individuals' emotions can and do arise, and differences of opinion among family members about the patient's values and wishes can have a significant—and potentially deleterious—impact on courses of treatment and care [30].

Part of the explanation for this phenomenon is that human nature, despite individuals' best intentions, is often fraught with errors that influence how accurately people access a memory, recall an episode, and activate a "cognitive scene" for a particular purpose, especially when the circumstances are intense or complex [31]. A patient's stated wishes, family members' recollection of such, and our assessments of what others value can be similarly flawed. For example, the research on "[substituted judgment](#)," in which family members of an incapacitated patient are surveyed in an attempt to understand the incompetent patient's prior preferences, shows it is often not nearly as accurate as most people might imagine—or prefer—it to be [32]. In addition to incorrect inferences being made, the decision may be further complicated by cognitive biases, such as the "hot-cold empathy gap," in which people often "mispredict" and do not fully appreciate how they and others will think, feel, and behave across different affective states and environments [33, 34]. As a result, "best interests" standards, often involving family input, are increasingly being incorporated due to concerns about the inability of family to generate reliable substituted judgments [35, 36].

## Conclusion

Despite the imperfections of implementing best interest and substituted judgment standards of decision making, allopathic health care still embraces family involvement and remains rather suspicious of "pure" autonomy. Signs of this appear in US-based research, such as the Institute of Medicine report, *Crossing the Quality Chasm*, which advocated for increased transparency so that patients and their families could make more informed health care decisions [37], and statements from nonprofit organizations promoting family-centered care [38]. They also appear in the bioethics discourse, which includes the argument that respecting the patient autonomy (in terms of the direction of medical care) can involve the influence of others, such as family members, as well as physicians [39, 40].

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## IMAGES OF HEALING AND LEARNING

### We Got Your Back: Patient Advocacy Through Art

Regina Holliday



Figure 1. Detail of "For Him" by Regina Holliday

I often paint pictures of patients facing away from the viewer with their johnny gowns open in the back. Nurses who watch me paint at conferences chuckle at this well-known reality of patient life; physicians often ask why I painted it that way. "Isn't that disempowering? Why do you paint patients like that?" They ask me this with a furrowed brow and quizzical frown. I glance up from my current canvas and respond with a wry smile, "We are all patients in the end."

Art can be a vibrant method of [advocating for the interests of patients](#). Those paintings of johnny gowns led to painting *on* business suit jackets. I founded a movement called the Walking Gallery of Healthcare [1], in which patients and clinicians don business suit jackets with personalized health care story paintings on the backs.





Figure 2. Detail of "Training the Brier," a jacket for Catherine Costa by Regina Holliday

LJ, a manager at a pharmaceutical company, wears the story of his brother on his back. LJ's brother died of AIDS prior to ready availability of the drug cocktail that has helped so many. He tells his jacket story while working in pharmaceuticals and hopes to save lives in so doing. CK wears her jacket story that depicts her childhood self receiving food from the free or reduced lunch program. Now she guides federal health policies that contribute to population health. There are currently 43 artists painting the images in the Walking Gallery, and close to 400 jackets are worn on five continents. Now when patients turn their backs on viewers, their stories are being seen and told, conveying that



they are human beings who have been affected by illness or injury experiences or lapses in health care service delivery.



Figure 3. Participants in the Walking Gallery of Healthcare at the conference: Cinderblocks2: The Partnership with Patients Continues on June 4, 2015.

When I dove into the world of health care in 2009, I was researching my husband's advanced kidney cancer. I would scroll through article after article looking for a study or clinical trial that could help him. The walls of text loomed large before me, and I was amazed that there weren't many pictures or any other kind of visual draw to the information. I was surprised that a digital age that thrived on viral images and videos would stick to dry and scholarly text when explaining disease. Occasionally I would see a stock photo of smiling people with the accompanying text praising a new cancer center on a medical website. Or an abstract smear of color maybe intended to be comforting—an image that could be interpreted as anything or nothing at all—would grace an article focused on end-stage options. Where was the message art? Where was the art that made an impression? Where was the art that inspired action?

In 2009, while my husband, Fred, was sick and we struggled to get access to his medical record, I began painting a series of murals focused on data transparency and patient rights. I called this the "Medical Advocacy Mural Project." The 17-by-70 foot mural "73 Cents" [2] was named for the average cost per page the hospital charged to patients for

their medical records (taking into account the first-page charge \$21.69 and the 69 cents charged for each subsequent page, which is the maximum allowed by Maryland State Law [3]). The painting depicts our family journey in a closed data loop: The computer the nurse uses in the painting is turned off. We are unable to access the record through technology. We only have access to a few papers the nurse hands to us behind her back. This painting is used in some communication studies curricula to explain meaningful use of electronic health records and patient rights as they relate to data access. Fred would die before the work was completed, but he had faith that “73 Cents” and the mural project would help other patients and families by changing health policy. These murals became part of the national patient rights debate in the US, helping support two pieces of legislation: the ACA [4] and the Health Information Technology for Economic and Clinical Health (HITECH) Act of 2009 [5]. Within weeks of beginning the painting, I was able to present our story at a US Senate press conference focusing on the Affordable Care Act [6]. Within the year I was able to testify to the Meaningful Use Work Group of the Health Information Technology Policy Committee at the Department of Health and Human Services [7].

After completing the murals, in 2010 I began painting about the relation between clinical scores and patient satisfaction levels measured by Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) scores. Using data sets hosted on the Center for Medicare and Medicaid Service’s Hospital Compare website [8], I noted the very high clinical scores and the very low patient satisfaction scores at a local teaching hospital in Washington, DC. I painted the piece “Apples to Apples” [9] to explain to the average citizen that, although this hospital had great clinical scores, the patients inside the facility were not satisfied with their care. This painting was created *en plein air* in front of the facility, and throngs of passersby stopped to ask me where I got the data I was painting about. I responded that it was freely available online. I was very glad to inform patients that there were places they could look to find information about hospitals prior to admission. I entered this painting and a video of its creation in a competition hosted by the Sunlight Foundation, winning special honorable mention for best use of health data [10].

Next, I began live painting at medical conferences. Many concertgoers are familiar with live painting at musical venues, but medical conference attendees did not expect to see an artist painting about patient safety and data access at medical centers and hotel ballrooms. I would listen to the speakers throughout the day and paint an image based on their words from my worldview as patient and caregiver. Translating verbal messages into visual images is a skill set many graphic illustrators use to create illustrations that depict prominent themes of the day. Creating such images as a patient rights advocate combines a judicious depiction of the day’s presentations with an underlying message of patient empowerment. Often the venue allows me to explain the painting at the close of the conference and thereby magnify its reach. The mirroring back of the day’s themes in

both paint and story reaffirms the attendees' understanding of central themes. And the dual representation of information both verbally and visually allows a greater appreciation of it among attendees with a diverse range of learning styles. Finally, the painted image is more likely to live beyond the day of the event as visual images can be shared easily online.

I've suggested here that patient advocacy through art can be a vibrant method for creating positive change. I paint about health care, I blog about it, and I write poetry about this challenging time in health care. These poems often close speeches I give on the subject. Even though I am not the best singer, I wrote a song about being a widow, a health activist, and a mother. Two friends helped set it to music and we recorded it. I wrote a book revealing my entire life story in the hope that I could inspire others to fight for patients, too. I host medical conferences with fire dancers and doctors seated side by side, because [the arts united with medicine](#) is a mighty force for good. I hope that each of you who read this article is inspired to do the same—to use every talent and ability you have, medical or artistic, to make the world of health care a better place.

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**Regina Holliday** is a Maryland-based patient advocate and artist known for painting a series of murals depicting the need for clarity and transparency in medical records. She is the author of *The Walking Wall: 73 Cents to the Walking Gallery* (Health Informatics Society of Australia, 2012) and *The Writing on the Wall* (CreateSpace Independent Publishing, 2015).

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## MEDICAL NARRATIVE

### Taking Our Oath Seriously: Compassion for Patients

Ramy Sedhom, MD

Just a few months into residency, I realized the mutual vulnerability of patient and physician. As a healer, I've seen the physical risks faced by physicians fighting the Ebola virus. I've also occasionally felt rejected by the ingratitude and hostility of patients or their families. I've spent a few nights humbled with failure, questioning my abilities. Yet, what has been most difficult for me is the social context in which we practice our profession. I feel most compassion for the [people we often neglect](#). Illness can be a spiritual event. As physicians, we don't always pay attention to healing the soul as much as we do to healing the body. Paying closer attention to soul, however, is important, because it can be thought of as the seat of a person's dignity. Illness and death undoubtedly attack our dignity. The ill or injured are robbed of their control in life. Dignity cries out against that injustice. I've learned that I must recognize and protect the dignity of each person. Physicians have a moral duty to help bolster a patient's dignity, to understand when it is at risk. Too often, a patient's dignity is not recognized or affirmed.

I remember my first time [volunteering in a shelter](#). I was 15. It was the first time I removed the smelly socks of a homeless person. All the typical assumptions made about people who are homeless suddenly became relevant to me. We were separated by wealth, social power, and opportunity, but I had communicated to this person that he was worthy of my time and service, and, more importantly, I affirmed our equality. Yet, I felt a sense of vulnerability. I feared the possibility of rejection when I first introduced myself to him. Would he feel embarrassed that I was here to assist him? What do we even have in common to discuss? Was this going to be awkward? I was naïve and influenced by stereotypical views of homeless people as filthy, and so I worried I might contract a rare infectious disease by interacting with him. But I sat with him and asked about his story—what his childhood was like, the sports he played, and I learned of his favorite hobbies. We exchanged some words and a few laughs; we shared disappointment about the taste of pizza outside New York City. We spoke as equals. Years later, I recognize the social inequality denying the inherent worth of such people. My morning rounds are shaped by my experiences with those living with HIV, injection drug users, people with disabilities and dementia, and orphans. These are people whose dignity has already been assaulted by the erroneous assumptions we tend to make about them. Now, as a physician, I encounter these patients when they are sick and dying.

It's night float and my senior resident is quick to tell me that the case of a homeless person with schizophrenia from the streets in New Brunswick is "non-teaching," that is, will not be assigned to residents. A few hours later, the ER calls again; this time it's an elderly woman coming in from her nursing home who's confused. It's her fourth admission to the emergency department (ED) in the past two months. A few seconds pass. The ED case screener, jaded and fatigued, once again says, "I think I'll pass this one to non-teaching." Problematic to me was the assumption, expressed in this statement, that these patients have no teaching value to residents or medical students. This assumption reflects our failure to connect with patients on a spiritual or psychological level. All patients are worth a trainee's time. All patients are worth every clinician's time [1].

Patients who are sick need to be treated as persons, a kind of medical practice that acknowledges more than just what's empirically verifiable through standard measures of medical science. They may seek medical care that doesn't abandon science but also does not shun the spiritual or psychological dimensions of illness and injury. This ideal is often sought in alternative forms of medical care [2]. Medicine at its worst is a scientific practice untempered by humility and uninspired by awe. It is a blind science that ignores the person's soul, reducing the patient to a body. Our affliction in medicine is the loss of empathy for our common frailty and humanity. Human beings, body and soul, become sick and die. Medicine is not sometimes an art, and sometimes a science. It is always both art and science.

We might not admit it, but, as physicians, there are always patients whom we do not like. These include the so-called "difficult," the ungrateful, the noncompliant, the mentally compromised elderly, and the self-abusive. Caring for these patients is hard because it is thankless and often frustrating; we write prescriptions for medications that most likely will not be taken, and practice can feel fruitless. The forces that pushed patients into these situations—poverty, ignorance, and social injustice—seem insurmountable. What can one physician do? Each hospitalization seems like a drop in the sea of insoluble social problems. We do our best, but not always with smiles. Despite technological progress, we neglect the needs of whole persons and limit our attention to the finitude of human bodies. We forget what suffering and death mean and forego our role in offering hope. Illness disturbs more than the internal lives of patients. It disrupts families. It raises serious questions about our collective strengths and weaknesses. For patients, families, and physicians, illness can shatter preexistent methods of coping. The vulnerability, too often, is not shared enough.

There are system practices that try to improve compliance. Social workers now arrange services to help needy patients manage their difficult circumstances. Quality improvement committees meet daily to address pitfalls in care. Yet, despite our best intentions, we know that there are many things we cannot do as individual clinicians.



Noncompliance will not be eliminated. Mental illnesses will likely remain untreated. Poverty, ignorance, and social injustice breed so much of the disease we treat [3]. However, beyond our social differences is the way of compassion. Compassion is a deep response to the suffering of another. It is the art of healing. It relates to the core of the person who suffers, understanding the need for care and the sources of vulnerability. It is beyond an empathetic response, attempting to understand or know the suffering experienced by another. True compassion, true healing, can help address mutual vulnerabilities and restore damaged relationships.

A compassionate physician treats the subjective and the objective. Healing is dialectically inclusive [4]. This idea of *dialectical inclusivity* comes from Hans-Georg Gadamer, who took language to be not just a means to engage with the world, but the very medium for engagement. Applied to healthcare, this idea suggests that we are in the world through being in language, so the delivery of healthcare can be compared to Gadamer's idea of *hermeneutic experience*. That is, we must first and foremost treat persons, and also the social wrongs that exacerbate distress and obstruct healing. Allopathic medicine needs to pay closer attention to the nature and scope of healing that patients require. We must offer socially mediated responses to illnesses that go beyond individual cases. The science of allopathic medicine has advanced, but the art has not.

When asked, "Why do you want to be a doctor?," many of us probably mumble some words similar to our graduation oath. The words spoken might refer to service to humanity, love for people, and a desire to combine scientific knowledge with genuine care for others.

I try to take my oath seriously. I'm encouraged daily by new [students](#) filled with idealism, fervor, and zeal.

Caring for patients has not been easy. It's taxing to mind, body, and soul. But further reflection yields satisfaction in our daily practice. We have the privilege of entering deeply into people's lives—the darkest secrets and the most private triumphs. We share hope, fear, love, grief, and joy. We are all somebody. Our worth has no price—whether dirty or clean, rich or poor, expected to recover or bound to die, compliant or noncompliant, grateful or ungrateful. I'm reminded of the spiritual resonance of our practice daily by smelly feet.

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## SECOND THOUGHTS

### Evidence-Based Design: Structuring Patient- and Family-Centered ICU Care

Allyn Rippin, MS

Three decades ago, the Picker Institute set forth recommendations about how to include patients and families in care delivery [1]. Since then, patients' loved ones are increasingly recognized as vital to patients' healing processes, particularly during hospitalizations for acute and life-threatening conditions. In a typical adult intensive care unit (ICU), a priority is to protect patients from infections and stress. Restricting visitor access also protects staff space and privacy, enabling staff to focus on the hour-to-hour needs of patients. While this model has some important benefits, it also has some drawbacks that [patient- and family-centered care](#) (PFCC) models address. Specifically, PFCC replaces a hierarchical, clinician-centered model by treating patients' loved ones as partners in healing rather than visitors. Patient's family members, once restricted to 10-minute visits with patients every few hours, are now invited to be present continually—in some cases during rounds and shift changes. Significant cautions about and barriers to adoption of PFCC models of ICU care, however, need close attention and are considered in the rest of this article. But first, what are some of the important benefits of PFCC?

#### Benefits of PFCC Models of ICU Care

An ICU that invites family presence and participation fulfills many important social, emotional, and informational needs of patients' family members [2, 3]. According to a report from the American Association of Critical-Care Nurses, when family members are allowed to bear witness to lifesaving procedures and day-to-day care, they have less anxiety and greater confidence that everything is being done for their loved ones [4]. Likewise, when patients are unable to speak for themselves, family members often step in as surrogate decision makers, which can greatly influence clinical outcomes [5]. Ongoing communication of important information, such as medication history and changes in patients' conditions, can play a key role in safe and effective care delivery [6]. Family members are also invited to share personal narratives that ensure their loved ones' needs, values, preferences, and beliefs are incorporated into care plans [7].

#### Cautions about Implementing PFCC Models of ICU Care

Given the benefits just described, why would organizations hesitate to adopt and integrate PFCC models and practices? In some respects, PFCC may be easier to deliver in theory than in practice. A review of several decades of nursing literature shows that family presence in ICUs has always presented challenges for nursing staff. Increased family presence—around the clock, in some cases—requires clinicians to encounter

more people and to navigate a confluence of interpersonal, social, and cultural dynamics at the patient's bedside. Trying to determine the right tone or degree of transparency in delivering information to an anxious family can be a delicate balancing act, especially for new nurses [8]. Moreover, each family member handles stress differently. Being on the receiving end of some members' dysfunctional ways of coping with a loved one's illness or injury can increase stress among staff [9]. Nurses' experiences suggest how clinicians are expected to attend to the needs of many stakeholders other than the patient. At times, boundaries must be placed and affirmed when family members' needs compete with those of patients—for example, when a sick patient needs to rest while a family seeks reassurance at the bedside [10]. Some nurses have argued that the sickest patients (e.g., those with neurological or coronary conditions) need additional safeguarding, even from loved ones' good intentions [11]. So, resisting implementation of PFCC models that prioritize the needs of patients' loved ones can, in some cases, be an important way of protecting patients' best clinical interests.

### **Physical Barriers to Implementing PFCC Models of ICU Care**

The physical layout and design of ICU space can also pose significant barriers to integrating PFCC. Studies have shown, for example, that when nurses consider patient rooms small and uncomfortable, family presence is discouraged [12]. Clinician-centered design prioritizes staff and patient privacy, whereas evidence-based design (EBD) supports integrating clinical tasks with safety and transparency. A growing body of research suggests that good design can help reduce infections, decrease stress, shorten length of stay, and facilitate other positive health outcomes [13]. Strategically placed sinks that encourage hand washing, decentralized nursing stations with direct visibility to patients for improved safety, and sunlit rooms with views of nature to relieve stress are just a few EBD recommendations set forth by industry experts [14].

Likewise, design can play an important role in facilitating PFCC. Key principles of PFCC, including greater communication and collaboration, are facilitated by how the ICU environment is structured. Physical elements such as glass instead of solid walls, larger patient rooms with wider berths around bedsides, and private meeting spaces are EBD changes that can make PFCC more likely to be a natural part of everyday life in the ICU. In one study, for instance, family presence at the bedside increased when rooms provided comfortable seating [15]. A study I conducted with my colleagues showed that nurses working in renovated, family-centered neurological ICUs found these environments more conducive to PFCC than clinician-centered models and that they facilitated more efficient informed consent processes [16].

Conversely, our study also found that these same spatial qualities of co-visibility and proximity between staff and family increased potential for clinicians being interrupted at their workstations and exacerbated clinicians' self-consciousness about being watched [16]. The PFCC model requires clinicians to relinquish some workplace privacy and

control otherwise afforded by clinician-centered environments. Our study demonstrated that this loss of privacy and control may contribute to high levels of clinician stress without organizational resources and support to facilitate the transition to this new care environment. These findings illustrate that switching from a clinician-centered model to a PFCC model requires organizations and clinicians to trade the benefits of one model for the benefits of the other.

Today, architects are challenged with designing ICUs that simultaneously nurture clinicians' needs while accommodating the needs of patients and family members. While decision making is guided, in part, by emerging evidence and industry guidelines, multiple perspectives and experiences from those actually occupying the ICU space on a daily basis must be considered in tandem [17]. Cross-disciplinary input from clinicians and feedback from patients and families is vital for designing ICU spaces that are efficient and effective. As such, architects are increasingly utilizing focus groups and simulation labs (e.g., prototypes, full-scale room mock-ups) to test design concepts, gather practice knowledge, and—as an interdisciplinary team—weigh advantages and drawbacks. Not all clinicians support family presence, but attitudes and behaviors towards family involvement are changing, particularly as clinicians gain more experience working alongside families [18]. Stakeholder inclusion in design processes can further help dissolve lingering resistance to PFCC by encouraging the co-creation of optimal solutions. By integrating research with practice, this collaborative approach not only helps facilitate the adoption of PFCC among staff, but also fulfills a commitment to PFCC values of *collaboration*, *knowledge sharing*, and *partnership*.

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#### **Related in the *AMA Journal of Ethics***

[Patient- and Family-Centered Care: It's Not Just for Pediatrics Anymore](#), January 2016  
[Moving Past Individual Autonomy: The Rise of Family-Centered Patient Care](#), January 2016

[Crowded Conditions: Coming to an ER Near You](#), November 2006

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## CORRESPONDENCE

### Physician Health Programs and the Social Contract

Philip J. Candilis, MD

*This correspondence responds to J. Wesley Boyd's "[Deciding Whether to Refer a Colleague to a Physician Health Program](#)," which appeared in the October 2015 issue, 17(10), of the AMA Journal of Ethics.*

Physician health is a special area of medical practice that raises critical ethical questions for practitioners and organizations. As diversion programs for impaired or disruptive physicians that allow limitation, suspension, or revocation of medical licensure to be diverted if they maintain safe practice, physician health programs (PHPs) can be administered by state medical societies, state medical licensing boards, or third parties. Decisions to refer, monitor, or reintegrate physicians into the profession must consequently balance those physicians' needs with patient safety and call on the ethics of the social contract in a way that may not be familiar to many physicians. An example of this lack of familiarity appeared in these pages recently [1]. In that article, PHP efforts to maintain physician adherence to treatment are characterized as coercive—"Failure to comply with any aspect of the [PHP] contract can, and often does, result in being reported to the licensing board." Moreover, the piece raised questions about whether physicians in PHP programs can even give "noncoerced, informed consent" to participate in research [1]. To characterize the pressures that keep physicians committed to PHP requirements and the efforts to study PHP practices as coercive does not recognize the ethical framework of the social contract, which is critical to this discussion.

Colleagues, employers, family members, and physicians themselves can alert state licensing boards or PHPs to a physician's health or behavioral problems. Yet physicians and their families may not expect the stringency with which boards and PHPs respond to their concerns. Requirements that physicians undergo assessment, treatment, or supervision, or temporarily refrain from practice, can be devastating for impaired practitioners struggling to maintain relationships with their patients, families, or colleagues. Referral to a PHP is often a powerful warning for dedicated professionals losing their battle with work-life balance or substance abuse. Thankfully, empirical studies of PHPs show strong success and satisfaction rates among those who engage in treatment; the literature consistently reports 75 percent or better success rates over the decades [2-6].

The article in question makes other claims about PHPs as well. One is that financial “relationships between the PHPs and the evaluation and treatment centers create financial incentives for each to act in ways that favor the other’s interests” [1]. Although new research is an available tool for assessing the adequacy of this claim, there is as yet no evidence that PHPs have a financial incentive to refer physicians to treatment programs. Sponsorship of conferences by programs with specific expertise working with troubled clinicians—an example the author suggests as an illustration of such a conflict—occurs within organizational, professional, and educational guidelines established throughout medicine.

The article also asserts that “physicians who object to state PHP recommendations are often not taken seriously” [1], citing a controversial North Carolina audit that criticized the state PHP’s due process protections. Although it is beyond the scope of this letter to analyze the North Carolina audit, I can mention here that due process protections are available to PHP participants through numerous sources, including hospital bylaws, employment contracts, and board regulations. Furthermore, physicians with concerns about PHP recommendations are not without recourse; they have the resources to hire employment attorneys who are familiar with the workplace challenges of physician impairment and reinstatement.

The article also contains the claim that PHPs “often receive very little scrutiny” [1]. Yet PHPs answer to their boards of directors, to sponsoring medical boards or medical societies, and to the hospitals, medical schools, and practices that consult them. In my experience with PHPs, while physicians are closely assessed and monitored, medical boards and PHPs are no strangers to tight scrutiny either.

Most important, however, are the author’s claims of coercion. Describing the PHP model as coercive is inappropriate for several reasons: First, PHPs are voluntary outlets for physicians who wish to stay ahead of potential impairment or board sanction. The diversionary option of a physician health program allows physicians a path to re-enter or remain in the profession rather than face suspension or revocation of their licenses. It is physician workplaces or state boards that mandate physician participation; PHPs themselves do not discipline or force physicians to participate. As stringent as they may be, referrals are not a bar to all employment—indeed, the fact that state boards and PHPs use reporting mechanisms indicates that they recognize the effectiveness of tying treatment adherence specifically to future medical practice. Although physicians may not be able to practice their chosen vocation, their voluntary participation is part of a larger construct: the social contract.

In psychiatry, for example, it is not new to recognize relationships between psychiatrists and their licensure boards (as agents of the state) as a social contract [7, 8]. Physicians agree to practice in a professional manner in exchange for the privilege to practice

specialized interventions that would be illegal if conducted by any other citizen. Unlicensed citizens are not permitted to cut into patients, prescribe controlled substances, or conduct clinical evaluations without that special privilege. The social contract is an agreement entered by professionals and governments (as public representatives) that secures a benefit, a right, to the public. The possibility of mandated board intervention is part of that social contract. The social contract—through licensure and credentialing agreements—confers a benefit to society: the right of individual citizens to expect safe medical practice. For PHPs to fulfill ethical, legal, and professional reporting obligations found in the American Medical Association *Code of Medical Ethics* [9] and in guidance from state boards is part of this broader social context.

Because of the social contract, it is appropriate that oversight agencies require impaired physicians to undergo rehabilitation. This is simply part of the societal agreement governing professional licensure. As difficult as oversight is for impaired physicians, the right of the state to take action against the licenses of impaired physicians on behalf of the public is not controversial [7]. Licensure and credentialing bodies' primary obligation is to protect patients; holding and maintaining a license to practice medicine is consequently a privilege that can be regulated, limited, or suspended by the state in the interest of public health and safety.

Next, coercion is not applicable to PHPs because physicians are not a vulnerable group for whom the term coercion is typically invoked. Referring to coercion is appropriate when describing exploitation of vulnerable or disadvantaged populations, research participants, or patients who have less medical knowledge than their physicians. It is not easily applicable to physicians themselves, who are already socially privileged and trained in the requirements of teamwork, professionalism, and self-care. This is not to minimize the painful nature of medical or mental illness among physicians; indeed, many physicians do not recognize how susceptible they are to burnout and emotional fatigue—conditions with a lifetime prevalence of 15 to 20 percent [10-12]. But despite these susceptibilities, physicians are governed first by the agreement that privileges their practice rather than gratuitous threat suggested by the language of coercion.

Boyd, in his article and in another setting [1, 13], goes so far as to assert that conducting research with PHP participants is also coercive. This improperly conflates concerns about pediatric, obstetric, and correctional research with research on adults with intact decision-making ability. Although some physicians in PHPs may lack capacity to consent to research, they cannot be presumed to lack autonomy as a group, and should not be thought of as vulnerable in the manner of research participants who have been assessed formally as lacking decision-making capacity. Government regulators considered, as criteria for research approval, additional protections for vulnerable populations like children, prisoners, pregnant women, mentally disabled persons, and those who are educationally or economically disadvantaged [14]. They did not envision including

physicians among the vulnerable groups. Common informed consent practices, confidentiality measures, and institutional review board oversight sufficed. As they should.

Ultimately, coercion is not a satisfactory description of the opportunity for impaired or disruptive physicians to regain their professional standing. When Bonnie and Monahan [7, 8] wrote of professional licensing and its parallels with mandated outpatient treatment, they framed it as an opportunity to increase available options rather than to limit individual rights. The more adversarial language of coercion, used by Boyd, is not useful for an important social collaboration that achieves the collective goal of safe and professional practice. It is the social contract that more constructively describes this critical societal interaction.

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## Suggested Readings and Resources

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