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# Person- and family-Centered Care: A Time for Reflection

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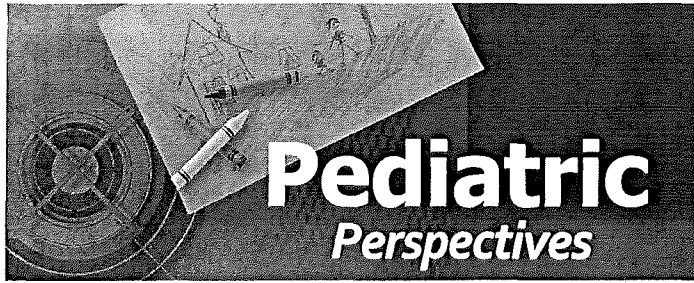
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# Pediatric Perspectives

Mary Frances D. Pate, RN, PhD, CNS  
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## Person- and Family-Centered Care: A Time for Reflection

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In 2007, the Pediatric Perspectives column was launched in *AACN Advanced Critical Care*. The journey began with an “in the balcony” look at the state of pediatric acute and critical care nursing. Over the years, the column has covered various topics specific to the youngest population of patients. Although exciting interventional and technological advances have been made during this time, has person- and family-centered care (PFCC) implementation moved forward as quickly as other aspects of care? This question became reality as one of the authors of this article exited an interstate ramp only to look up and see billboards, a few blocks from a children’s hospital, with statements such as “Children’s hospital X does not provide evidence-based visiting hours” and “Children’s hospital X does not do family-centered care.” Interestingly, at the bottom of each billboard were references from evidence-based articles to validate the statements. These large reminders of gaps in care remained at the exit ramp for 3 months. It was clear, at least for the patient and family in need of telling their story, that improvements in PFCC are needed. This column reflects upon this challenge.

### Background/Significance

Historically, people were born at home, cared for when ill, and then died at home, surrounded by loved ones. In pediatric hospitals, children and parents were separated during hospital stays from the 1900s to 1950s. Visiting policies were loosened in the 1960s, when pediatric hospital design allowed more space for visitors and when consumers requested greater access, but these changes were less prevalent in pediatric intensive care units.<sup>1</sup> In 2006, a study across varied intensive care units (ICUs) (adult, pediatric, neonatal) showed that 75% were not open for visitation at all times.<sup>2</sup>

An informal search of the Cumulative Index to Nursing and Allied Health Literature yielded articles related to family-centered care starting in the early 1960s. Most articles during the earliest years were from maternity nursing journals. Neonatal and pediatric literature on the topic soon followed. The literature has used various terms to describe the important partnership and collaboration with patients trusted to the care of health care providers; these terms have evolved from *family-centered care* to *patient- and family-centered care* to the most current *person- and family-centered care*. During the 50-year span since the first articles

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were published, nurses practicing in the areas of maternity, neonatal, and pediatric populations have continued to serve as leaders in PFCC.

Numerous professional, volunteer, accrediting, governmental, and independent organizations have endorsed the practice of intentional, meaningful collaboration with patients and families (eg, American Association of Critical-Care Nurses, American Academy of Pediatrics, Institute of Medicine, American College of Critical Care Medicine, American Heart Association, American Nurses Association, Society of Critical Care Medicine, Centers for Medicare & Medicaid Services, The Joint Commission, Institute for Healthcare Improvement, Institute for Patient and Family-Centered Care, Patient and Family Centered Care Innovation Center). These organizations endorse this work because of the substantial body of evidence that cites the benefits, but inexplicably, debate on the merits of PFCC persists among health care professionals.

### Professional Responsibility

As professionals, nurses have a social contract with society to provide competent, quality health care.<sup>3</sup> Knowing the current best evidence related to patient care and not using it (provided no contraindications are present) would put nurses at odds with professional responsibility and ethical, just care.<sup>4</sup> Nurses must use not only evidence that is convenient but all of the available best evidence to provide quality, excellent care to patients and families if the social contract with society is to be maintained. Consider the professional and ethical frameworks used as an individual nurse and as a workplace to make decisions about patient and family care. For example, why might it be permissible not to follow evidence related to PFCC, but essential to follow the best evidence related to pediatric trauma or cardiac care?

Health care providers in busy, technology-focused ICUs may become overwhelmed and disconnected from the feelings and perspectives of others. Recently, increased attention has been given to initiatives aimed at restoring empathy in the health care environment, so that the vital connection with patients and families can be nurtured and maintained.<sup>5,6</sup>

### Ethical Responsibility

In ICUs, ethical and human rights issues may emerge if pediatric patients are unable to assert their rights.<sup>4</sup> In contemplating respect, dignity, and the rights of the patients and fami-

lies nurses serve, Rushton<sup>7</sup> provided points to consider: What does it mean to honor a person's inherent human dignity? What actions demonstrate the intention to understand and individualize care that is consistent with what matters most to the person? How do we create the conditions for demonstrating respect as a dynamic and reciprocal process?

Collaborating with patients and families in the ICU attests to the ethical principle that every human has a right and duty to participate in society according to the level of need and responsibility due him or her. In other words, every person has a right and duty to participate in society and thereby enjoy the fruits of companionship according to his or her mental and physical capacities. Any rejection of the substantial evidence that supports this type of collaboration gives the appearance of paternalism. Such violation of ethical principles includes reducing the holistic care of the patient to provide a controlled environment that may reflect the needs of health care providers more than the needs of the patient and family, thereby providing health care provider-centered care instead of PFCC.

Care of the whole person is important as nurses integrate interventions that nurture the physical, emotional, and spiritual well-being of healthy, social, human beings. In terms of the ethical imperative involved in supporting PFCC, initiatives such as open visitation, family presence during codes and procedures, and inclusive bedside rounds may serve as an ethical barometer that judges the overall spiritual health of the organization.

### Discussion

The evidence is clear that collaboration between health care providers and patients and families is of benefit to both. Multiple organizations have called for this intentional, vital partnership. However, the question must still be raised: Why do 75% of ICUs surveyed still restrict access to patients in ICUs? As health care providers, we must make time for reflection and decision making about PFCC implementation.

Providers who want to move forward with PFCC implementation should engage with organizations championing this initiative and build collaborative relationships with nurses in maternity, neonatal, and pediatric practice, as these providers have been on the leading edge of innovations in the area of PFCC. That being said, these

pioneering providers cannot become complacent and should always be looking to the future, considering new ways to advance PFCC. Those in organizational leadership positions can serve as catalysts for implementation through role modeling evidence-based behaviors and adding PFCC competencies to annual performance reviews.

We echo the challenge made by Donald Berwick<sup>8,9</sup> to eliminate restrictions on visiting hours in ICUs, so that true partnerships and authentic collaboration can occur between patients and families and health care providers. Although open visiting is only 1 component of PFCC, only when families have full access to loved ones can these vital partners become fully engaged members of the interprofessional team. When this step occurs, we hope that there will be no need for roadside billboards.

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