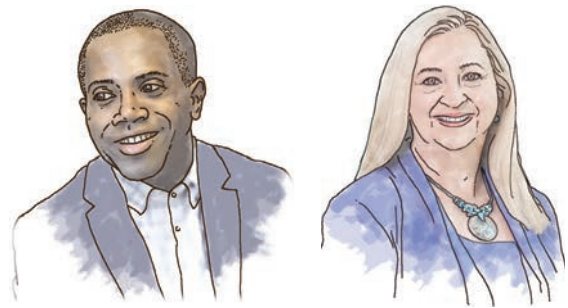


Editorial

DECLARATIONS ON PATIENT AND FAMILY ENGAGEMENT

By Aluko A. Hope, MD, MSCE, and Cindy L. Munro, PhD, RN, ANP



In the years leading up to the COVID-19 pandemic, all sectors of the health care system seemed to be in the midst of a cultural and political movement toward more patient engagement and participation.¹ As the pandemic recedes, we think it is worth interrogating how these participatory practices can truly transform the care we provide in the intensive care unit (ICU), particularly for our most vulnerable patients. In the ICU, patients and families have long been expected to be involved in their own clinical care. The shift toward more engagement with patients and their families has meant that we are increasingly asking patients and families to participate in the design and implementation of our research studies, our quality improvement projects, and our organizational or health system reforms. The rationale for this commitment to engagement is sound: it acknowledges that the lived experience and expertise of our patients and their families have the potential to make clinical care, research, and quality improvement more patient centered.²

Initiatives like the healthtalk.org website have an extensive catalog of patient and family experiences on film, including a recently funded section showing patients' and families' experiences of severe COVID-19 in the ICU during the pandemic.³ Patients can assess

the quality of the health care they received through satisfaction surveys such as the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey, which increasingly can affect the reimbursement provided by health insurance providers.⁴ Patient and family advisory councils (PFACs) provide a structure within which health systems can engage with the perspectives of patients and families while also helping their clinicians better appreciate the needs of their patients. The American Hospital Association recently published a toolkit for building and sustaining a successful PFAC.⁵ One of the key strategies recommended in the toolkit is that health systems include staff members to ensure that the council's activities are meaningfully integrated into the changes and improvements within the health system. The toolkit highlights some potential strategies for ensuring that nurses remain integral to the culture of patient and family engagement: creating PFAC champions among bedside nurses in each unit; engaging nursing students with PFAC work; and involving patient advisors in nursing education to ensure that nurses remain integral to the cultural revolution of patient and family engagement.

On the research front, the Patient-Centered Outcomes Research Institute funds research projects in which the engagement of patients, caregivers, clinicians, insurers, and other relevant stakeholders within the health care community is strong. Other federal

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funding agencies for research in the United States are increasingly judging clinical research by how well the researchers are engaging with patients in all aspects of the research, including topic development, design and conduct of the research, and the dissemination of the results. The James Lind Alliance, a nonprofit initiative based in the United Kingdom, aims to bring patients, caregivers, and clinicians together in priority-setting partnerships to identify and prioritize unanswered questions or evidence uncertainties that are the most important to patients and families and the health care professionals who care for them.⁶ In 2014, for example, the Alliance engaged clinicians, patients, and family members over the course of 15 months to establish priorities for ICU research.⁷

Professional societies have long involved patients and/or their families in task forces, on committees, and as speakers at their annual conferences. The American Thoracic Society, for example, has the Public Advisory Roundtable, which since 2001 has aimed to incorporate patients' and families' perspectives into the activities of the organization. The Society of Critical Care Medicine has the Patient and Family Committee, which aims to provide information and resources to patients and their families about the ICU experience, including end-of-life issues. The challenges of meaningful engagement with patients and families in the ICU have been captured in recent clinical reviews and include wide variability in the willingness to engage in participatory practices; patient, family, and organizational barriers to participation; and risks to patients, families, clinicians, and researchers.⁸ Yet we do not think that these recent writings go far enough to interrogate the potential impact of these participatory practices on health inequities.

Burns et al⁸ conducted an interview-administered survey of visitors across pediatric and adult ICUs

about (1) preferences for engagement topics, methods, and activities; (2) their perceived facilitators and barriers to patient and family engagement; and (3) perceptions regarding importance, impact, and willingness to participate. These researchers found that the study participants prioritized the kind of clinical engagement that involved information exchange or education, and they found that less than 5% of the respondents wanted to be involved in committee meetings that met regularly.⁹ In the same study, visitors to pediatric ICU patients expressed more confidence that their involvement would be impactful and were more likely to engage than were visitors to adult ICU patients.⁹ This finding may suggest that the care we provide to adults in the ICU seems so far removed from our patients' lives in the communities from which they come that we may need to do more listening to really understand how best to frame patient and family engagement across the ICU settings. The ethical complexities of patient engagement in the ICU include a small but real potential for harm to the participants.^{8,10} Patient and family engagement often involves participants sharing or reliving their experiences in the ICU, which could exacerbate symptoms of depression or posttraumatic stress disorder. Patients and families may feel disappointed if their recommendations are not acted on and may lose trust in the health care system. Patients and families may feel embarrassment or guilt or other complex emotional or affective responses during their participation, and they may not feel comfortable sharing those responses during the engagement process.

The biggest challenge to patient and family engagement's being able to realize its potential for transforming our care in the ICU, however, is the spirit in which such engagement is often conducted. Too often, patient and family participation simply becomes a perfunctory way to meet the administrative goals set by those in power within the clinical, education, or research systems. Hahn et al¹¹ highlight 3 key domains that can be used to distinguish genuine engagement from mere tokenism: the first domain involves the structure and process of the engagement, including such things as paying attention to the group composition and management,

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scheduling, communication, and feedback; the second domain involves the intention of the engagement and includes such strategies as involving the stakeholders in determining the goals, outcomes, and objectives; and the third domain involves paying attention to the relationship-building potential before, during, and after the project, which can involve looking for opportunities to build trust and solidarity as well as delving into and addressing differences in culture or expectations.

Too often, the voices that are speaking for “patients and families” are self-selected, from one culture or from one linguistic background. Too often, the voices that are speaking for our patients and families are from advocacy organizations interested in fighting for more access to primary or specialty health care, more high-tech innovation, or more pharmaceutical interventions for diseases we manage. Community organizations that have been fighting for more social or economic support for our patients are often excluded from these conversations. The patients and families who are too impaired and those who lack the necessary social or financial resources (whether it be a computer or a quiet room in which to sit and listen to a virtual meeting or the necessary transportation to attend an in-person meeting) are not typically invited to participate. The patients and families who cannot afford to take time off from work or school or from their important social roles are not typically invited to participate. The patients or families who do not trust the health care system or who are intimidated by the participation process will not typically be invited to participate. And so, the very nature of these participatory practices, including the people we typically include and excluding the people we typically exclude, too often serves to maintain the inequities in the status quo. For patient and family participation to truly transform the care we provide for all our patients, including our most vulnerable, we must be willing to make what we do in the ICU relevant to our patients’ health in the communities in which they live. Our most vulnerable patients

have “petitioned [us] for redress in the most humble terms,”¹² and if we want to ensure that these petitions are not “met with more repeated injury,”¹² we must be willing to ensure that our engagement processes prioritize the insights and expertise of the most vulnerable among us, the most disenfranchised.

The statements and opinions contained in this editorial are solely those of the coeditors in chief.

FINANCIAL DISCLOSURES

None reported.

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