

# Advancing the Practice of Patient- and Family-Centered Care: *The Central Role of Nursing Leadership*

Susan M. Grant, DNP, RN, NEA-BC, FAAN, and Beverley H. Johnson, BSN, FAAN

National focus on increasing patient and family engagement in care to improve outcomes continues to intensify as health systems shift to care models that support population health. However, health systems struggle to understand exactly how to effectively engage patients and their families in care. This article focuses on strategies implemented by 4 health systems in different regions of the country to improve patient and family engagement and nursing leadership's pivotal role in advancing the practice of patient- and family-centered care.

During the last 2 decades, there has been growing recognition that partnerships with patients and families at the direct care level and in improvement and culture transformation initiatives enhance quality, safety, and the experience of care.<sup>1,2</sup> As a safety strategy, internationally recognized health care leaders stated that “organizations [should] publicly and consistently affirm the centrality of patient- and family-centered care.”<sup>3(p.426)</sup> In 2012, the Institute of Medicine, in its landmark publication, *Best Care at Lower Cost: The Path to Continuously Learning Health Care in America*, included the core recommendation: “Patients and families should be given the opportunity to be fully engaged participants at all levels, including individual care decisions, health system learning and improvement activities, and community-based interventions to promote health.”<sup>4(p.31)</sup> Since 2011, large-scale improvement initiatives for hospitals and ambulatory care funded by the Centers for Medicare & Medicaid Services have integrated partnerships with patients and families into the work.<sup>5</sup>

Although these goals are recognized by many health care leaders as the right things to do, it is not always apparent *how* leaders and frontline clinicians can effectively engage patients and families in all levels of decision-making. Nurse leaders are uniquely positioned to lead change in organizational culture and to advance patient- and family-centered care (PFCC) because of their broad scope, depth of understanding of health systems, and daily connection with patients, families, clinical staff, and administrators.

## PATIENT- AND FAMILY-CENTERED CARE AS THE FOUNDATION FOR ORGANIZATIONAL CULTURE

PFCC is an approach to the planning, implementation, and evaluation of health care that is grounded in mu-

tually beneficial partnerships among patients, families, and health care professionals across all disciplines. The core concepts of respect and dignity, information sharing, participation, and collaboration are foundational to organizational culture. [Table 1](#) details the concepts.

Operationalizing PFCC core concepts leads to transformational change. The following presents stories of profound and sustained change in organizational culture in 4 regions of the United States and how nursing leadership played a critical and instrumental role in creating a culture to advance the practice of PFCC.

## DANA-FARBER CANCER INSTITUTE

The tragic death of Betsy Lehman due to a massive overdose of chemotherapy and the realization that staff and clinicians had not listened to patient and family concerns led the Dana-Farber senior leadership team in 1995 to commit to PFCC and provide philosophy and processes to respect and learn from patient and family perspectives and experiences. Initial steps included the

### KEY POINTS

- Patient engagement is the key to transforming health care delivery and yielding improved patient outcomes.
- Health care systems struggle to understand strategies to effectively engage patients and their families in care.
- Nursing leadership can play a critical role in advancing the patient engagement and the practice of patient- and family-centered care.

**Table 1.** Patient- and Family-Centered Care: The Core Concepts

- People are treated with **respect and dignity**.
- Health care providers communicate and **share complete and unbiased information** with patients and families in ways that are affirming and useful.
- Patients and families are **encouraged and supported in participating in care and decision-making** at the level they choose.
- **Collaboration** among patients, families, and health care professionals occurs in policy and program development, safety and quality improvement, professional education, and research, as well as in the delivery of care.

Adapted from *Partnering With Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-term Care Communities*.<sup>6</sup>

creation of a partnership between the chief nursing officer (CNO), chief medical officer (CMO), and chief operating officer (COO), who partnered with patient and family advisors (PFAs) to establish a Patient and Family Advisory Council (PFAC). The CNO, CMO, and COO set expectations for Dana-Farber that PFCC would be central to all patient safety, quality, and organizational initiatives. The PFAC drove many leadership actions that ultimately transformed the culture at Dana-Farber. Key leadership actions taken included:

- Visible commitment and investment in education for leaders, staff, and clinicians to increase awareness and understanding of PFCC
- Implementation of a PFAC and broad dissemination of its minutes to educate leaders and clinicians across Dana-Farber and build trust in the collaborative process
- Appointment of PFAs as members of the board quality committee
- Elimination of the visitor policy restricting family access in the bone marrow transplant unit
- Implementation of PFA inpatient rounding with the CMO and CNO after the move to a new hospital
- Implementation of a PFA newsletter distributed to all patients, families, staff, physicians, and to the community

#### UNIVERSITY OF WASHINGTON MEDICAL CENTER

The year 2000 was a challenging time for Seattle and the University of Washington Medical Center. Boeing, the largest employer in the state, moved its corporate offices to Chicago, which created the need for significant budget reductions. The CNO looked for help in making decisions in response to community priorities. Building on the successful experience of Dana-Farber, the CNO and nursing leadership felt that a commitment to PFCC and authentic partnerships with patients and families would provide a way to be guided by what was most important to patients, families, and communities.

As a first step, nursing leadership engaged the Institute for Patient- and Family-Centered Care (IPFCC) to conduct a comprehensive assessment of organizational culture to identify existing partnerships with patients and families and PFCC practices. Results were used to create a roadmap to build on existing strengths in PFCC and to develop a plan for areas in need of change and improvement.

A PFCC steering committee of senior leaders was appointed to address barriers and challenges identified in the assessment. As support grew for PFCC, nursing leadership created 2 paid positions: a dedicated position for PFCC leadership within the department for patient education and interpreter services; and a patient and family advisor to coordinate and facilitate the PFCC program. These positions provided expertise and support for nursing and department leaders to partner with patients and families and focus on needed improvements in their areas.

A major result was the development of a robust, patient and family advisory program with multiple PFACs (oncology, perinatal, rehabilitation, intensive care unit, and facilities) and advisor participation in over 15 organization-wide committees. PFAs participated in the reduction of falls initiative, hand washing campaign, and changing practice to include families in neonatal intensive care unit rounds. PFAs also participated in interviewing medical students applying for the obstetrics/gynecology residency and later taught first- and second-year residents about communicating with women in respectful and helpful ways related to prenatal care, childbirth, complications, and decision-making.

#### EMORY HEALTHCARE

In 2006, as the nation's focus on improving patient safety and quality, pay for performance, and engaging patients in meaningful partnerships in improvement intensified, Emory Healthcare embarked on a journey to develop a comprehensive strategy to transform its culture to improve patient outcomes and organizational performance. The CEO, who was committed to

improving patient safety and quality, recognized that to achieve this transformation, there must be innovative approaches in care delivery that would fundamentally change the work of clinicians and employees.

The CEO appointed a leadership team that included the system level CNO, who brought expertise in PFCC. With the CEO's support, the CNO educated the senior leadership team and the governing board on the "why" for PFCC and how it was foundational to transforming culture and improving quality and safety. In partnership with the chief quality/medical officer and the chief human resources officer, the CNO led the development of a care delivery model with PFCC at its center to use as a framework for the organization's journey to care transformation. Key actions taken by the leadership team included:

- Development of a philosophy that viewed PFCC as the foundation for everything done in the health system and that the organization's core values and teamwork would guide and enhance the practice of PFCC
- Leadership commitment to broad-scale, ongoing PFCC education across disciplines and departments
- Identifying PFCC as a strategic priority and highlighting PFCC annual goals in the strategic plan
- Creation of PFACs across the enterprise as well as a system-level PFAC to guide organizational decision-making
- Engagement of over 200 PFAs in the organization's most important initiatives and membership on key committees and the board of trustees
- Nursing and departmental leadership engagement in implementation of enterprise-wide policies that supported family presence and eliminated visiting hours
- Integration of PFCC by nursing leadership into their professional practice model, which aligned with the Magnet<sup>®</sup> framework and actions underway for achieving Magnet designation
- Strong nurse leader engagement in the development of a system-wide, standardized shift hand-off process that engaged patients and families at the bedside and included PFAs as trainers for this change in practice for nursing staff
- PFA participation in the building of the system's first patient- and family-centered neuroscience intensive care unit that provided a private space for families to room in next to the patient

Emory Healthcare's intense focus on PFCC, quality, and safety led the organization's 2 largest hospitals achieving a national ranking of #2 and #3 in 2013 in the University Health System Consortium's Quality Leadership Awards. The adoption of a bedside change-of-shift report resulted in a 40-point improvement in the Hospital Consumer Assessment of

Healthcare Providers and Systems item "Nurses kept me informed," as well as reduction in pressure ulcers, falls, and use of restraints.<sup>6</sup> Emory's model was featured in an Agency for Healthcare Research and Quality guide.<sup>7</sup> And in 2014, the teamwork and collaborative relationships with clinical leaders grounded in patient- and family-centered practice enabled the health system to successfully accept and treat the nation's first 2 patients with Ebola virus disease without any breach of infection-prevention practices or contraction of the virus to caregivers.

## BEAUMONT HEALTH

Beaumont Health was established in 2014 as a result of the coming together of 3 different health care organizations, resulting in the creation of the largest health system in southeastern Michigan. In 2015, a new CEO was brought in from Emory Healthcare to lead Beaumont Health. As an executive leader with a strong background in finance and health system leadership, he had seen what a commitment to PFCC and the formation of authentic partnerships with patients and families could do to transform organizational culture and to improve overall organizational performance.

Within his first month, the CEO requested that IPFCC conduct an assessment of PFCC practices and opportunities for improvement in Beaumont's 2 largest hospitals. He had great respect for the role of nursing leadership to lead the implementation of PFCC across the health system, and in his first year, he hired a system-level executive vice president and chief nursing officer with PFCC knowledge, skills, experience, and commitment. IPFCC conducted additional assessments at the 6 remaining hospitals, home care and hospice, skilled nursing facilities, and Beaumont Medical Group and Ambulatory Clinics.

Using this information, nursing leadership along with members of the senior leadership team developed a health system strategic plan that included its core values and PFCC as the foundation for strategic goals and future planning. The first 3 strategic goals for 2016 were thoughtfully considered and established to create a tangible change in practice for all departments and disciplines that demonstrated leadership's commitment to creating a patient- and family-centered culture. Those goals included elimination of restrictive visiting policies and implementation of best practices for family presence and participation<sup>8</sup>; implementation of a comprehensive and standardized approach to bedside shift report across Beaumont<sup>7</sup>; and creation of site-based PFACs and a system-wide PFAC.

An organizational commitment was made to provide broad-scale ongoing education across departments, disciplines, and the board of directors to facilitate a common understanding of PFCC. Ultimately, the organization set a "moonshot" goal for 2022 to galvanize all members of the organization around a common

**Table 2.** Building the Infrastructure to Support and Sustain Effective Partnerships With Patient and Family Advisors

Serve as or identify executive sponsor(s) for patient- and family-centered care.

Dedicate resources to support a staff liaison for collaborative endeavors with patient and family advisors (PFAs) to:

- Develop a recruitment strategy, application process, and selection criteria for potential advisors
- Orient and mentor advisors for their specific roles
- Work with the volunteer department or human resources department to assist with recruitment, screening, selection, orientation, training, and recognition of PFAs and maintenance of a database documenting advisors' involvement.

Provide resources to prepare administrative, clinical, and staff leaders to collaborate on teams and committees, and facilitate meetings so that partnerships with PFAs are meaningful and productive.

Invest in the development of patient and family leaders—experienced PFAs who can facilitate or lead councils and other collaborative initiatives as volunteers as well as in paid positions to oversee and coordinate patient and family advisory programs.

Adapted from *Partnering With Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-term Care Communities*.<sup>6</sup>

vision of becoming the national exemplar for PFCC. The setting of the moonshot goal and demonstrated support from the CEO and board of directors precipitated significant leadership actions, including the creation of a vice president for PFCC and director for PFCC. Individuals, whose careers in PFCC began as PFAs, were hired into these positions. They brought patient and family perspectives into organizational decisions and discussions, and their insights and presence have accelerated progress toward the moonshot goal.

Milestones and leadership actions toward the moonshot goal include:

- Further investment in broad-scale PFCC training for staff and clinicians, with special focus on physician and leader training
- Development of a nursing professional practice model with PFCC at the core of the model with engagement of PFAs and over 4000 nurses in its development
- Creation of a moonshot dashboard and metrics to measure organizational progress toward advancing PFCC
- Site-specific goals on increasing the number of PFAs
- Standardizing PFCC training and education materials for all volunteers, staff, and physicians in partnership with PFAs
- Implementation of site-based PFCC champions to offer coaching and expertise to frontline clinicians who are implementing PFCC practices
- Creation of the Reach the Moon grant program to inspire innovation in PFCC practices across Beaumont
- Creation of a PFCC researcher position to lead patient- and family-centered research exploring

the relationship between PFCC practices and outcomes

## IN CONCLUSION

The stories of sustained, transformational change in 4 health care organizations illustrate key lessons learned that can inform future nursing executive leadership roles. Among these are:

- Organizational commitment to education for senior leaders and the governing body are key to establishing a common understanding of and vision for a culture of PFCC.
- Embedding PFCC goals explicitly in the strategic plan, making these goals visible to the organization, communicating executive leaders' and board of directors' clear commitment, and demonstrating that PFCC matters are essential to success.
- PFCC is not just a nursing initiative! CNOs and other nurse leaders are uniquely positioned to lead PFCC; however, they must demonstrate that PFCC lives in all disciplines and departments including nonclinical areas. Partnerships with other disciplines and clinical leaders of quality and safety are necessary to bring about change.
- Physician leadership and human resources leadership play a key role, and nursing leadership can be instrumental in forming and fostering partnerships.
- PFCC naturally serves as a foundation to efforts surrounding achievement of Magnet designation. PFCC efforts contribute to creating a professional practice environment where nurses are able to connect with patients and families in meaningful ways that enhance the patient experience, quality, and safety; the nurses' professional practice;

**Table 3.** Key Leadership Roles for Nurse Executives

The Nurse Executive:

Builds understanding of patient- and family-centered care (PFCC), its connections to quality and safety, and its benefits.

Provides resources to conduct a PFCC assessment of organizational culture and policies, programs, and practices to identify strengths and opportunities for improvement.

Provides resources to create and sustain meaningful partnerships with patients and families across the continuum of care.

Makes an explicit commitment to PFCC and serves as a role model for partnering with patients and families.

Addresses institutional barriers to PFCC.

Creates opportunities for leaders, managers, clinicians, and staff to learn about PFCC and the related partnerships with patients and families.

Educates and garners support from other senior leaders and the governing board for implementation of PFCC best practices and related strategies.

Ensures that advancing the practice of PFCC is a priority in the organization's strategic plan.

Ensures that patient and family advisors are meaningfully involved in the following:

- Changing and improving care practices
- Developing, implementing, and evaluating new programs
- Developing and revising patient and family informational and educational materials
- Planning for changes to the built environment
- Expanding the use and usefulness of information technology
- Serving as members of organizational committees such as board-level safety and quality and strategic planning committees
- Serving as faculty for staff orientation and continuing education and in the education of students and trainees
- Partnering in evaluation and research.

Puts systems in place to measure the outcomes of collaborative processes.

Recognizes that profound organizational change takes time.

Celebrates the successes and recognizes individuals who work to advance the understanding and practice of PFCC.

Adapted from *Partnering With Patients, Residents, and Families: A Resource for Leaders of Hospitals, Ambulatory Care Settings, and Long-term Care Communities*.<sup>6</sup>

the work environment; and ultimately, nursing-sensitive outcomes.

- Partnerships with PFAs are critical. See [Table 2](#) for key steps to build infrastructure for an effective PFA program.

Further information about the central role of nurse leaders in advancing the practice of PFCC is listed in [Table 3](#).

To ensure that nurse leaders of the future are prepared to advance the practice of PFCC, opportunities for leadership development need to be enhanced and education for this role needs to be embedded at all levels of nursing education. These dimensions of leadership

and their impact on transforming health care delivery should be further developed through research.

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Susan M. Grant, DNP, RN, NEA-BC, FAAN, is executive vice president and chief nursing officer at Beaumont Health in Southfield, Michigan. She can be reached at Susan.[Grant@beaumont.org](mailto:Grant@beaumont.org). Beverley H. Johnson, BSN, FAAN, is president and CEO at the Institute for Patient- and Family-Centered Care in Bethesda, Maryland.

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