

## Patient- and Family-Centered Care: Partnerships for Quality and Safety

By: Beverly H. Johnson, Marie R. Abraham, and Terri L. Shelton

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### **Article:**

#### CORE CONCEPTS OF PATIENT- AND FAMILY-CENTERED CARE

Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care. Patient- and family-centered care also offers a framework within which to begin examining policies, programs, and practices and for hospitals, ambulatory practices, and agencies that choose to do so, to begin on a journey to transform organizational health care culture.

As defined by the Institute for Family-Centered Care, patient- and family-centered care is guided by the following four concepts:<sup>1</sup>

- *Dignity and respect.* Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs, and cultural backgrounds are incorporated into the planning and delivery of care.
- *Information sharing.* Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
- *Participation.* Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
- *Collaboration.* Patients and families are included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; health care facility design; and professional education. Patients and families also collaborate in the delivery of care.

## WHY IS PATIENT- AND FAMILY-CENTERED CARE IMPORTANT?

Because of its focus on participation and collaboration, patient- and family-centered care means working *with* patients and families rather than doing *to* and *for* them. It makes families, patients, and health providers partners in care. In patient- and family-centered care, patients define who their family members are and how they will be involved in care and decision-making. Partnerships with families are essential because for the patient, the families are the constant—the link across different settings. Their presence for ambulatory care appointments, hospital stays, and especially during the planning for transitions in care can help ensure quality and safety.

The basic tenets of patient- and family-centered care (e.g., respectful partnerships, open communication, shared decision making, and strength-based approaches) often run counter to the ways in which health care has traditionally been taught and practiced. More recently, patient- and family-centered concepts and strategies are being incorporated into health policy legislation;<sup>2</sup> respected national organizations are issuing policy statements and publications that support patient- and family-centered practice;<sup>3</sup> and funding agencies are encouraging researchers to study patient- and family-centered policies and practices and include patients and families in the research process itself.<sup>4,5</sup>

An accumulating body of research demonstrates that patient- and family-centered care benefits everyone involved —patients, families, health care providers, and payers. Moreover, its benefits are substantial. Patient- and family-centered care is increasingly linked to improved health outcomes; lower health care costs; more effective allocation of resources; reduced medical errors and litigation; greater patient, family, and professional satisfaction; increased patient/family self-efficacy/advocacy; and improved medical/health education.<sup>6-14</sup>

## EXAMPLES OF EMERGING BEST PRACTICES IN PATIENT- AND FAMILY-CENTERED CARE

Ambulatory medical practices, hospitals, and health systems today are increasingly integrating patient- and family-centered approaches and concepts into their daily operations, as demonstrated by the following examples:

- Patients and families are supported and encouraged in being essential members of the health care team across the continuum of care.
- Collaborative self-management support, an approach where patients and families are encouraged and supported in setting goals and action plans, has become the standard for managing chronic conditions in ambulatory settings.
- Families are no longer viewed as visitors and signs are no longer posted on hospital walls that indicate the hours during which families may be with a loved one. They are involved as allies for quality and safety in clinics, at the bedside, and in the community.
- Rounds are conducted in a manner that facilitates the involvement of the patient and, according to patient preference, the family.
- Nursing change of shift report is conducted at the bedside with the patient and family.
- Charting and documentation systems in primary care, ambulatory settings, and hospitals capture the goals, priorities, preferences, concerns, and observations of patients and families and ensure patient, family, and clinician access to information.
- Patients and families are involved in transition and discharge planning.

- Patient and family advisors are partners for change and improvement in health care settings and in institutions educating future physicians. They serve as family faculty in academic medical centers and schools of medicine, where they play key roles in educating students, residents, and fellows.
- More and more hospitals are establishing patient and family advisory councils and involving these advisors in a variety of quality improvement and patient safety initiatives.

## GROWING NATIONAL AND STATE MOMENTUM FOR PATIENT- AND FAMILY-CENTERED CARE

As individual ambulatory practices, hospitals, and health systems continue to advance the practice of patient- and family-centered care, there is also tremendous momentum at national and state levels. As outlined below, momentum is building for partnerships with patients and families not only as active participants in care and health care decision-making but also as advisors and partners in teaching, quality improvement, and redesigning our health care system. Increasingly, these examples demonstrate the evolution from patient- and family-centered as a “nice thing to do” to a recognition that delivering care in this manner is integrally tied to larger issues of quality and safety.

### NATIONAL MOMENTUM

In 2004, the American Hospital Association, together with the Institute for Family-Centered Care, developed tools that define patient- and family-centered care and how leaders, trustees, and senior executives can foster this approach to care.<sup>15</sup> This partnership illustrates how the principles of patient- and family-centered care are increasingly linked with quality care. For example, the prestigious AHA McKesson Quest for Quality Prize for hospitals has integrated partnerships with patients and families throughout the award criteria, encouraging patient and family participation in rounds, providing access to their medical records, and changing the concept of families as visitors.<sup>16</sup> The award recognizes hospital leadership for aligning the agendas for quality, safety, and patient- and family-centered care.

One of the Joint Commission’s patient safety goals specifies involving the patient as a patient safety strategy. The Joint Commission has developed several resources that describe partnerships with patients and their families and offer strategies for moving forward with patient- and family-centered care.<sup>17,18</sup>

Similarly, patient and family engagement is the first of six priorities in the National Priorities Partnership Action Agenda to Improve Health Care, a report funded by the Robert Wood Johnson Foundation and developed and endorsed by the Centers for Disease Control and Prevention, the Centers for Medicare and Medicaid Services, the Agency for Healthcare Research and Quality, the Institute of Medicine, the Institute for Healthcare Improvement, the Joint Commission, National Quality Forum, National Committee for Quality Assurance, the National Business Group on Health, the National Governors’ Association, and 18 other organizations.<sup>19</sup> The core concepts of patient- and family-centered care provide a framework and strategies to achieve these priorities.

While the principles are clearly evident in the tenets of the medical home for children, efforts are underway nationally to bring about major change in *adult* primary care through the Joint

Principles for the Patient-Centered Medical Home.<sup>20</sup> These principles, all of which are closely tied to those of patient- and family-centered care, include the following:

- The care-planning process is driven by a compassionate, robust partnership between physicians, patients, and the patient's family.
- Patients participate actively in decision-making.
- Care is coordinated and/or integrated across all elements of the health care system (e.g., subspecialty care clinics, hospitals, home health agencies, nursing homes) and the patient's community (e.g., family, public and private community-based services) in a culturally and linguistically appropriate way.
- Information technology is utilized to support optimal patient care, performance measurement, patient education, and enhanced communication.
- Patients and families participate in quality improvement at the practice level.

An excellent summary of this national groundswell can be found in the 2008 publication of the Institute for Family-Centered Care, *Partnering with Patients and Families to Design a Patient and Family-Centered Health Care System: Recommendations and Promising Practices*.<sup>21</sup> The publication synthesizes results of an invitational expert panel convened by the Institute for Family-Centered Care in collaboration with the Institute for Healthcare Improvement. The report's recommendations are illustrated by examples drawn from health facilities and other organizations that have made exemplary progress in partnering with patients and families. The expert meeting and report were funded by the Robert Wood Johnson Foundation and the California HealthCare Foundation.

#### STATE LEVEL MOMENTUM

Action at the state legislative level has also been noteworthy in recent years. For example, in 2008 the state of Massachusetts enacted legislation stipulating that every hospital in Massachusetts must have a patient and family advisory council and a process established for patients or families to call a rapid response team if there are concerns that the patient's condition is deteriorating.

BlueCross and Blue Shield of Massachusetts, a major payer for health care in that state, has created an annual \$100,000 industry best-practice award. It presented the Dana-Farber Cancer Institute with last year's award for its commitment to patient- and family-centered care and to partnerships with patients and families. Patients and family advisors serve on 92 organizational committees at Dana-Farber.

Since 2002, Minnesota has had a statewide collaborative to develop pediatric medical homes. From the beginning, primary care physicians and practices have partnered with families in this quality improvement initiative. In 2008, the Minnesota legislature passed legislation creating health care homes and stipulating that the standards for health care homes must be developed collaboratively with patients and their advocates and support the active participation of the patient and family in decision-making and in developing care plans. A consumer advisory group is participating in developing these standards.

## MOMENTUM FOR FAMILY-CENTERED CARE IN NORTH CAROLINA

### *University Health Systems of Eastern North Carolina, Greenville, North Carolina*

University Health Systems of Eastern North Carolina (UHS) is a regional health system serving 29 counties in eastern North Carolina. UHS includes Pitt County Memorial Hospital (PCMH), several community hospitals, physician practices, home health, and other independently operated health services. PCMH, an 861-bed tertiary care center, is the flagship hospital of UHS and serves as the teaching hospital for the Brody School of Medicine at East Carolina University.

Significant efforts to advance patient- and family-centered care at PCMH began in the late 90s. Many successes continue to be realized in Women's Services, the Children's Hospital, and in the Regional Rehabilitation Center. This progress and success, while valuable for these service lines, proved ineffective in advancing a patient- and family-centered culture throughout the organization. For patients and families utilizing multiple service lines in the organization, this had the potential to create a sense of inconsistency in their experience of care.

Over the past 18 months, multiple strategies have successfully utilized to advance the practice of patient- and family-centered care with the ultimate goal of transforming organizational culture within PCMH and throughout UHS. Recognizing that leadership was key, initial efforts concentrated on building and enhancing support from the executive team, the Board of Trustees, medical staff, and senior leadership. Patient and family-centered concepts and strategies have been integrated within UHS through its strategic and quality plans. A new office of Patient and Family Experience with a full-time director has been created. A basic tenet of the five-year quality plan is that "quality and safety work is patient- and family-centered."

At UHS, patients and their families are no longer viewed as visitors but as partners in health care. At every point of contact, the message is communicated that patients and families are a part of the team. The hospital's new patient handbook reinforces the message that patients and families are not passive recipients of care, but allies for quality and safety. Patient and family advisors, called Family of Care Associates, are being integrated across the system including membership on interview teams for hospitalist candidates, editorial review committees for patient and family education, and on the development of transparency tools for quality and safety measures.

Perhaps the most significant sign of progress is the change in the hospital's restrictive visitation policy. Early in 2009, the four intensive care units (surgery, trauma, medicine, and neurology) at Pitt County Memorial Hospital and the East Carolina Heart Institute changed the rigid visiting policies to flexible guidelines that support family presence and participation. To garner support at the staff level for this significant change in practice, over 160 staff champions are providing education for colleagues, recruiting patient and family advisors, and working together to identify opportunities to maximize quality, safety, and the experience of care at UHS. To assure the comfort and safety of patients in the East Carolina Heart Institute, staff conduct regular "glitch" rounds with patient and family advisors to proactively address safety concerns.

With commitment to transparency, safety, and quality improvement, information about central line infections and ventilated associated pneumonia is posted on the doors at the entrance to the ICU used by patients, families, and visitors. Patient and family advisors were involved in the

development of this communication and in providing information to patients and families about how they can assist in preventing these infections.

### *Perinatal Quality Collaborative of North Carolina*

The Perinatal Quality Collaborative of North Carolina (PQCNC) was formed in 2007.<sup>22</sup> Initially the Collaborative convened providers, families, payers, state agencies, legislators, non-governmental organizations, and hospitals, guided by the African proverb "to go fast, go alone, to go far, go together." All 29 neonatal intensive care units (NICUs) in the state are working together to implement an online survey to gather perceptions of parents. In partnership with William E. Edwards, section chief for neonatology at Dartmouth Hitchcock Medical Center, the units will launch the first formal survey that will gauge readiness for discharge and will begin to collect and use the voice of the parents to improve the discharge process for every family and baby who begin their journey in a NICU. Multidisciplinary teams that include parents are finalizing the spring 2009 launch in each setting.

The PQCNC vision is to generate the greatest possible value in perinatal health in North Carolina. PQCNC is committed to the dissemination of best quality practices and the optimization of health resources in a manner that is fully family-centered. In determining what role families might desire in this process, PQCNC convened two statewide family meetings, attended by parents who have had children in the NICU and family support specialists. The goal was to provide family members and support specialists the opportunity to meet, discuss critical issues, and advise PQCNC on how the family voice should be incorporated in the organization.

The message was clear—family members did not want to be part of a “family committee.” They wanted to be represented at all levels of the organization and have a voice in the statewide and local direction of PQCNC. As a result, families will have active roles in projects within NICUs and will serve on local perinatal quality improvement teams. In addition, parents are serving on the PQCNC leadership team that guides the development of the organization and new initiatives. Integrating the family perspective at all levels of the organization allows PQCNC to think broadly about perinatal quality improvement and to work toward the organization’s goal to make North Carolina the best place to be born. This action-oriented group is committed to improving outcomes, improving the experience of the family, and getting the best value for each health care dollar spent.

### **MOVING FORWARD IN NORTH CAROLINA**

The state of North Carolina is well positioned to support expanded partnerships among physicians and other health care professionals, community and state leaders, and patient and family advisors to continue building a system of care that is patient- and family-centered and enhances outcomes, quality, safety, and cost effectiveness. Ongoing initiatives in the state such as developing the medical home and redesigning primary care, expanding health care facilities, integrating patient- and family-centered concepts into graduate and undergraduate medical education, and health services research provide timely opportunities as does the state’s record in incorporating family-centered care principles in children’s mental health and most recently in adolescent substance abuse and juvenile justice. Other states have shown that engaging policymakers supports the process of change toward a more patient- and family-centered system of care. Partnerships with patient and family advisors, as exemplified in this commentary, are

essential to building bridges among clinicians in hospitals, community programs and practices, and with policymakers at all levels within the state in order to achieve quality outcomes for all.

**Table 1: Tools to Get Started**

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In addition to the references below, the following tools available from the Institute for Family-Centered Care will be helpful to anyone interested in moving forward with patient- and family-centered care.

*Advancing the Practice of Patient- and Family-Centered Ambulatory Care: How to Get Started*  
<http://familycenteredcare.org/pdf/GettingStarted-AmbulatoryCare.pdf>

*Advancing the Practice of Patient- and Family-Centered Care: How to Get Started (In Hospitals)*  
<http://familycenteredcare.org/pdf/getting-started.pdf>

Compendium of bibliographies/supporting evidence  
<http://familycenteredcare.org/advance/supporting.html>

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REFERENCES

1. Conway J, Johnson BH, Edgman-Levitan S, et al. *Partnering With Patients and Families to Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future—A Work in Progress*. Bethesda, MD: Institute for Family-Centered Care; 2006.  
<http://www.familycenteredcare.org/pdf/Roadmap.pdf>. Accessed March 9, 2009.
2. Minn. Stat. Chapter 358—S.F. No. 3780 Article 2: Health Care Homes; 2008.  
<http://www.health.state.mn.us/healthreform/legislation/sf3780article2.pdf>. Accessed March 10, 2009.
3. Committee on Hospital Care; American Academy of Pediatrics and Institute for Family-Centered Care. Family-centered care and the pediatrician's role. *Pediatrics*. 2003;112(3 pt 1):691-697.
4. Clancy CM. How patient-centered healthcare can improve quality. *Patient Safety & Quality Healthcare*. Mar-Apr 2008. <http://www.psqh.com/marapr08/ahrq.html>. Accessed March 9, 2009.
5. Patient-centered care. The Commonwealth Fund website.  
<http://www.commonwealthfund.org/Topics/Patient-Centered-Care.aspx>. Accessed March 9, 2009.
6. Seyda B, Shelton TL, DiVenere N. Family-centered care: why it is important, how to provide it, and what children and families are doing to make it happen. In: Earp JA, French EA, Gilkey MB, eds. *Patient Advocacy for Health Care Quality: Strategies for Achieving Patient-Centered Care*. Sudbury, MA: Jones and Bartlett; 2008:61-91.
7. Earp JA, French EA, Gilkey MB, eds. *Patient Advocacy for Health Care Quality: Strategies for Achieving Patient-Centered Care*. Sudbury, MA: Jones and Bartlett; 2008.
8. Stewart MA, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. *J Fam Med*. 2000;4(9):796-804.
9. Sweeney L, Halpert A, Waranoff J. Managing end-of-life care in complex patients can reduce costs without shortening life. *Am J Manag Care*. 2007;13(2):84-92.

10. Marks R, Allegrante JP, Lorig K. A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: implications for health education practice (part I). *Health Promot Pract.* 2005;6(1):37-43.
11. Marks R, Allegrante JP, Lorig K. A review and synthesis of research evidence for self-efficacy-enhancing interventions for reducing chronic disability: implications for health education practice (part II). *Health Promot Pract.* 2005;6(2):148-156.
12. Charmel PA, Frampton SB. Building the business case for patient-centered care: patient-centered care has the potential to reduce adverse events, malpractice claims, and operating costs while improving market share. *Healthc Financ Manage.* 2008;62(3):80-85.
13. Spath PL, ed. *Engaging Patients as Safety Partners: A Guide for Reducing Errors and Improving Satisfaction.* Chicago, IL: Health Forum; 2008.
14. Sodomka P. Engaging patients and families: a high leverage tool for health care leaders. *Hosp Health Netw.* 2008;(August):28-29.
15. American Hospital Association, Institute for Family-Centered Care. *Strategies for Leadership: Patient- and Family-Centered Care.* American Hospital Association website. <http://www.aha.org/aha/issues/Quality-and-Patient-Safety/strategies-patientcentered.html>. Accessed March 9, 2009.
16. AHA-McKesson Quest for Quality Prize criteria. American Hospital Association website. <http://www.aha.org/aha/news-center/awards/quest-for-quality/criteria.html>. Accessed March 9, 2009.
17. McGreevey M, ed. *Patients as Partners, How to Involve Patients and Families in Their Own Care.* Oakbrook Terrace, IL: Joint Commission Resources; 2006.
18. Pillow M, ed. *Patients as Partners: Toolkit for Implementing National Patient Safety Goal #13.* Oakbrook Terrace, IL: Joint Commission Resources; 2007.
19. National Priorities Partnership sets action agenda to improve health care. Robert Wood Johnson Foundation website. <http://www.rwjf.org/pr/product.jsp?id=33971>. Accessed March 9, 2009.
20. American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, and American Osteopathic Association. *Joint Principles of the Patient-Centered Medical Home; March 2007.* <http://www.medicalhomeinfo.org/Joint%20Statement.pdf>. Accessed January 2, 2009.
21. Johnson B, Abraham M, Conway J, et al. *Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: Recommendations and Promising Practices.* Bethesda, MD: Institute for Family-Centered Care; 2008. <http://www.familycenteredcare.org/tools/downloads.html>. Accessed March 9, 2009.
22. Welcome to the Perinatal Quality Collaborative! Perinatal Quality Collaborative of North Carolina website. <http://www.pqcnc.org/>. Accessed March 10, 2009.