
The Patient- and Family-Centered Care Imperative

Beverly H. Johnson
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In our time together . . .

- ▼ Define the core concepts of patient- and family-centered care and how they are applied to the development of medical homes and the redesign of primary care.
- ▼ Describe emerging best practices for patient- and family-centered care and partnering with patients and families in primary care redesign.
- ▼ Discuss recommendations for partnering with patients and families in the redesign of primary care.

What is Patient- and Family-Centered Care?

System-Centered Care



Patient-Focused Care



Family-Focused Care



Patient- and Family-Centered 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.
- ▼ Individuals and families build on their strengths through **participation** in experiences that enhance control and independence.
- ▼ **Collaboration** among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.

Transforming Healthcare: A Safety Imperative

"We envisage patients as essential and respected partners in their own care and in the design and execution of all aspects of healthcare. In this new world of healthcare:

Organizations publicly and consistently affirm the centrality of patient- and family-centered care. They seek out patients, listen to them, hear their stories, are open and honest with them, and take action with them.

Leape, L., Berwick, D., Clancy, C., & Conway, J., et al. (2009). Transforming healthcare: A safety imperative, *BMJ's Quality and Safety in Health Care*.

<http://qshc.bmj.com/content/18/6/424.full> . . .
continued

Transforming Healthcare: A Safety Imperative (cont'd)

The family is respected as part of the care team—never visitors—in every area of the hospital, including the emergency department and the intensive care unit.

Patients share fully in decision-making and are guided on how to self-manage, partner with their clinicians, and develop their own care plans. They are spoken to in a way they can understand and are empowered to be in control of their care."

<http://qshc.bmj.com/content/18/6/424.full>

Building National Momentum for Advancing the Practice of Patient- and Family-Centered Care

Laying the Groundwork for Change Institute of Medicine



Why Patient- AND Family-Centered Care?

Social isolation is a risk factor.

The majority of patients have some connection to family or natural support.

Individuals, who are most dependent on hospital care, are most dependent on families...

The very young;
The very old; and
Those with chronic conditions.

Entire issue devoted to Patient- and Family-Centered Care

April 2010



The Joint Principles for the Patient-Centered Medical Home . . . An Opportunity

- ◀ “. . . A care planning process driven by a compassionate, robust partnership between physicians, patients, and the patient’s family. . .
- ◀ Patients actively participate in decision-making. . .
- ◀ Care is coordinated and/or integrated across all elements of the complex health care system (e.g., subspecialty care, 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 appropriately to support optimal patient care, performance measurement, patient education, and enhanced communication.
- ◀ Patients and families participate in quality improvement at the practice level.”

Recovery Model of Care for Mental Health Services—SAMHSA and the Veteran Affairs Standard of Care



Long-Term Care Communities

Culture Change or Resident-Centered Care

Perham Memorial Home, Perham, MN

Partnering with older individuals, families, and the community for change in organizational culture and facilities . . .

The emerging data:

- ◀ Decrease in falls.
- ◀ Weight gain for frail patients.
- ◀ Reductions in negative behaviors.
- ◀ Increases in resident, family, and staff satisfaction.



The Joint Principles for Accountable Care Organizations (ACO)

- ◀ The ACO model was included in the Affordable Health Care Act that was signed into law in March 2010. The Medicare Payment Advisory Commission has requested the testing of ACOs for their potential to positively impact quality and efficiency of care and enhance cost effectiveness.
- ◀ As stated in the joint principles, “. . . primary care should be the foundation of any ACO and that the recognized patient and/or family-centered medical home is the model that all ACOs should adopt for building their primary care base” (p. 1)....

American Academy of Family Physicians, American Academy of Pediatrics, American College of Physicians, & American Osteopathic Association. (2010, November). *Joint principles for accountable care organizations*. Available from <http://www.aafp.org/online/en/home/media/releases/2010b/aco-jointprinciples.html>

Medical Home and Emerging Best Practices

How to Scale Up Primary Care Transformation: What We Know and What We Need to Know?

“Becoming a medical home is a radical change, requiring both a new mental model for primary care and the skills and resources to accomplish it.”

Homer, C. J., & Baron, R. J. (2010). How to scale up primary care transformation: What we know and what we need to know? *Journal of General Internal Medicine, 25*(6), 625-629.

How to Scale Up Primary Care Transformation: What We Know and What We Need to Know? (cont'd)

“In our experience, the unique perspective that family members bring refocuses transformation efforts away from provider concerns and toward bringing value for families and patients.”

Homer, C. J., & Baron, R. J. (2010). How to scale up primary care transformation: What we know and what we need to know? *Journal of General Internal Medicine, 25*(6), 625-629.

A Key Lever for Leaders . . . Putting Patients and Families on the Improvement Team

In a growing number of instances where truly stunning levels of improvement have been achieved...

Leaders of these organizations often cite—putting patients and families in a position of real power and influence, using their wisdom and experience to redesign and improve care systems—as being the single most powerful transformational change in their history.

Reinertsen, J. L., Bisagnano, M., & Pugh, M. D. *Seven Leadership Leverage Points for Organization-Level Improvement in Health Care*, 2nd Edition, IHI Innovation Series, 2008. Available at www.ihl.org.



Office-Based Quality Improvement Center for Medical Home Improvement

Pediatricians, family medicine physicians, and families working together to assure that all children have access to family-centered, culturally competent, coordinated, comprehensive primary care (*Pediatrics*, 2002).

Quality improvement methodology

- ◀ Core team: MD, Nurse or Case Manager, and a parent.
- ◀ Rapid cycle improvement.
- ◀ Developing a system of care, tracking, and monitoring children with special needs.

www.medicalhomeimprovement.org

Cooley, W. C., McAllister, J. W., Sherrieb, K., & Khulthau, K. (2009). Improved outcomes associated with medical home implementation in pediatric primary care. *Pediatrics, 124*, 358-364.

American Academy of Pediatrics National Center for Medical Home Implementation

<http://www.medicalhomeinfo.org/>

Dartmouth Hitchcock Medical Center Lebanon, NH

▼ Patient-Centered Medical Home

- Comprehensive, coordinated approach to primary care.
- Patient and family advisors – helped to define “good” access to care.
- Created a campaign to reduce the number of times they have to repeat their information.
- Helped shape the design of new ambulatory facility.
- Participated in interviews of key positions – physicians, nurses, social workers.



Dartmouth-Hitchcock
MEDICAL CENTER

Minnesota Medical Home Learning Collaborative

The process for the engagement of families:

- ◀ Each primary care practice team had at least two parents as members.
- ◀ Three times a year, all 23 teams gathered for a learning session. Family-centered care and parent/professional collaboration skills were taught to new teams. Veteran parents helped train new parent members.
- ◀ There was a state-level leadership team consisting of 12 to 15 members, mostly from the state government and academia, which met monthly. Some members were physicians. Two parents served on this leadership team.

Minnesota Health Care Homes



At the state level:

- ◆ There is an active Patient/Family Consumer Council. The Council developed a charter and the group provides advice for the Health Care Home program.
- ◆ Members of this Council serve on other committees as well as on Health Care Home certification site visit teams.

Oregon's Proposed Core Attributes and Standards for Patient Centered Primary Care Homes . . . written from patient perspectives

Core Attribute: ACCESS TO CARE

Be there when I need you.

- Make it easy for me to get care and advice when I need and want it for myself and my family members.
- Provide flexible, responsive options for me to get care in a timely way.

Standard: In-Person Access

- Make sure I can quickly and easily get an appointment with someone who knows me and my family.
- Ensure that office visits are well-organized and run on time.

Oregon's Proposed Core Attributes and Standards for Patient Centered Primary Care Homes . . . written from patient perspectives (cont'd)

Standard: Telephone and Electronic Access

- Make sure I know what to do if I need or want help when your office is closed.
- Provide multiple ways for me to easily get care or advice outside of office visits.

Standard: Administrative Access

- Respond to my requests for help with refills, paperwork, etc., in the most efficient way possible to meet my needs.
- <http://www.oregon.gov/OHPPR/HEALTHREFORM/PCPC/H/PCPCHStandardsAdvisoryCommittee.shtml>

Robert Wood Johnson Foundation's Aligning Forces for Quality Supporting Partnerships in Ambulatory Practices

Oregon Health Care Quality Corporation and PeaceHealth Medical Group—transformational change in ambulatory practices and health plans by supporting the development of sustained meaningful partnerships with patients and families at all levels of these organizations.

Maine Quality Counts providing resources and support to help ambulatory practices develop the structures, processes, and cultural change needed to effectively partner with patients and families to make practice improvements, enhance quality, and reduce costs for the larger healthcare system.

Patient and Family Advisors, PeaceHealth Medical Group, Eugene, OR



The **DVD Divas**...the inspiration for a patient safety video: Your Safety — Your Medications — Your Medical Visit

NCQA Updated Standards for Certification as a Patient-Centered Medical Home

▼ Robust patient centeredness is an important program goal:

- There is a stronger focus on integrating behavioral healthcare and care management
- Patient survey results help drive quality improvement
- Patients and their families are involved in quality improvement (NCQA, 2011, p. 1)

<http://www.ncqa.org/tabid/73/Default.aspx>

Redesign of Primary Care and the Management of Chronic Conditions



Collaborative Self-Management Support

- ▶ Information Sharing
- ▶ Goal Setting
- ▶ Action Plans

<http://www.newhealthpartnerships.org>
<http://www.chcf.org/topics/patient-self-management>

<http://www.teamupforhealth.org/>

Team Up for Health

Strategies

Comprehensive Approach to Organizational Change.
 Core Leadership Team.
 Performance Improvement Team with a Coach.
 Communications Training for Staff and Physicians.
 Patient- and Family-Centered Care and Partnerships with Patients and Families.

Results

Positive trends for patient perception of patient/provider communication, patient- and family-centered care, and self care.
 Positive trends in clinical and process measures (A1c, LDL, and blood pressure).
 Improved provider perceptions of the benefits of self-management support.
 Improvement in organization of health care delivery.

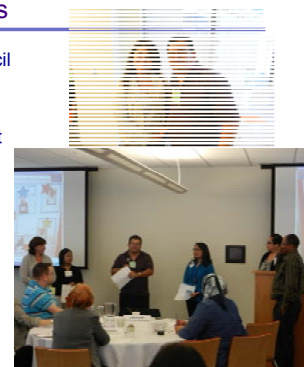


- ▼ A Patient and Family Advisory Council meets monthly.
- ▼ Participation in QI projects for wait times in the lab and the pharmacy refill process.
- ▼ A video storytelling project captures patient and family experience of care.
- ▼ Involvement of advisors in the clinic's patient portal project and in the development of a staff and provider reward and recognition program.
- ▼ An advisor serving as a member of the CMO search committee.
- ▼ Developed a notebook to track progress of the PFA Council.

NEVHC Preparing and Supporting Patient and Family Advisors

"I want to thank the Council for having me part of this work. When I share information about the changes we are making at the clinic with my family and friends in the community, I feel better about myself as a diabetic trying to manage my condition."

Oswalda Davila,
 Patient Advisor



Team Up for Health Humboldt Open Door Clinic

Redesigning the clinic's bulletin boards.

Helping to improve community resource referrals.

Reviewing the telephone system.

Developing a patient/friendly business card for clinic patients.

Promoting provider engagement.



Patient Advisory Board

Team Up for Health Sharp Rees-Stealy Medical Group



Patient advisors participate in the communications training with physicians and staff.

Care Coordination . . . Building on patient and family preferences at end of life

Case Management Study Blue Shield of California: In an 18-month study, Managed Care members were blindly assigned to receive usual case management (UCM) and half to receive patient-centered case management (PCM). PCM included working with a care manager to develop individual goals based on disease state, treatment options, pain management, and end-of-life decisions.

- ◀Emergency room visits reduced by 30%.
- ◀Hospital admissions reduced by 38%.
- ◀Hospital days reduced by 36%.
- ◀Home care use increased by 22%.
- ◀Hospice use increased by 62%.
- ◀\$18,000 cost reduction per patient.
- ◀Total overall costs for PCM members was 26% less than the total for UCM members.
- ◀98% of patients and families report PCM useful, and 86% report improves quality of life.

American Journal of Managed Care, February 2007

Best Practices

- ▼ Create the expectation for partnerships with patients and families in all settings as a quality and safety strategy . . . AND involvement in change and improvement initiatives from the beginning.
- ▼ Appoint a staff liaison for collaborative endeavors, an individual with strong facilitation skills and access to organizational leaders.
- ▼ Ensure that there is a comprehensive plan to recruit, orient, and prepare advisors and the staff working with them.
- ▼ Create a variety of ways for patients and families to serve as advisors.
- ▼ Invest in patient and family leadership development.
- ▼ Ensure that there is a system in place to track collaborative initiatives and measure the impact.

Patient/Consumer Partnerships in Research



Engage patients/consumers in defining health services research agendas, as well as defining methods to evaluate the impact of system changes brought about by the application of evidence into practice.

Organizations conducting research should evaluate their patient/consumer involvement programs.

<http://www.nmha.org/index.cfm?objectid=BD37C83A-1372-4D20-C8CF5F3E1B568572>

Develop an Annual Report to Share the Story and Profile Benefits of Partnering with Patients and Families

Include the number of:

- ▼ Patient and family advisors involved as well as their roles and activities.
- ▼ Clinical areas represented.
- ▼ Staff involved in collaborative endeavors.
- ▼ Issues addressed, products developed, classes taught, peer support programs coordinated, and other activities—describe these issues, materials, activities, and outcomes (when available).
- ▼ Meetings held with community leaders, government agencies, potential funders, accreditors, others.

Develop an Annual Report to Share the Story and Profile Benefits of Partnering with Patients and Families (cont'd)

- ▼ Summarize evaluations of classes taught to other patients, families, students, staff, physicians, new employees.
 - ✓ Count the # of people who participate in classes.
 - ✓ Capture quotes from participants in classes.
 - ✓ Summarize stories that they share.
- ▼ Include changes in patient/family perceptions of care and clinical indicators.
- ▼ Take photographs (or scan) of products, activities, changes in physical spaces
- ▼ Maintain a collection of all the products developed collaboratively.

Changing the Culture of Organizations across the Continuum of Care . . .

A Journey, not a Destination

Partnering with Patients and Families is Key

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