

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

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Patient- and Family-Centered Care: Enhancing Quality and Safety Across the Continuum of Care

Beverley H. Johnson
Third National Medical Home Summit
Eleventh Annual Population Health and
Care Coordination Colloquium
National Palliative Care Summit
March 15, 2011



In our time together . . .

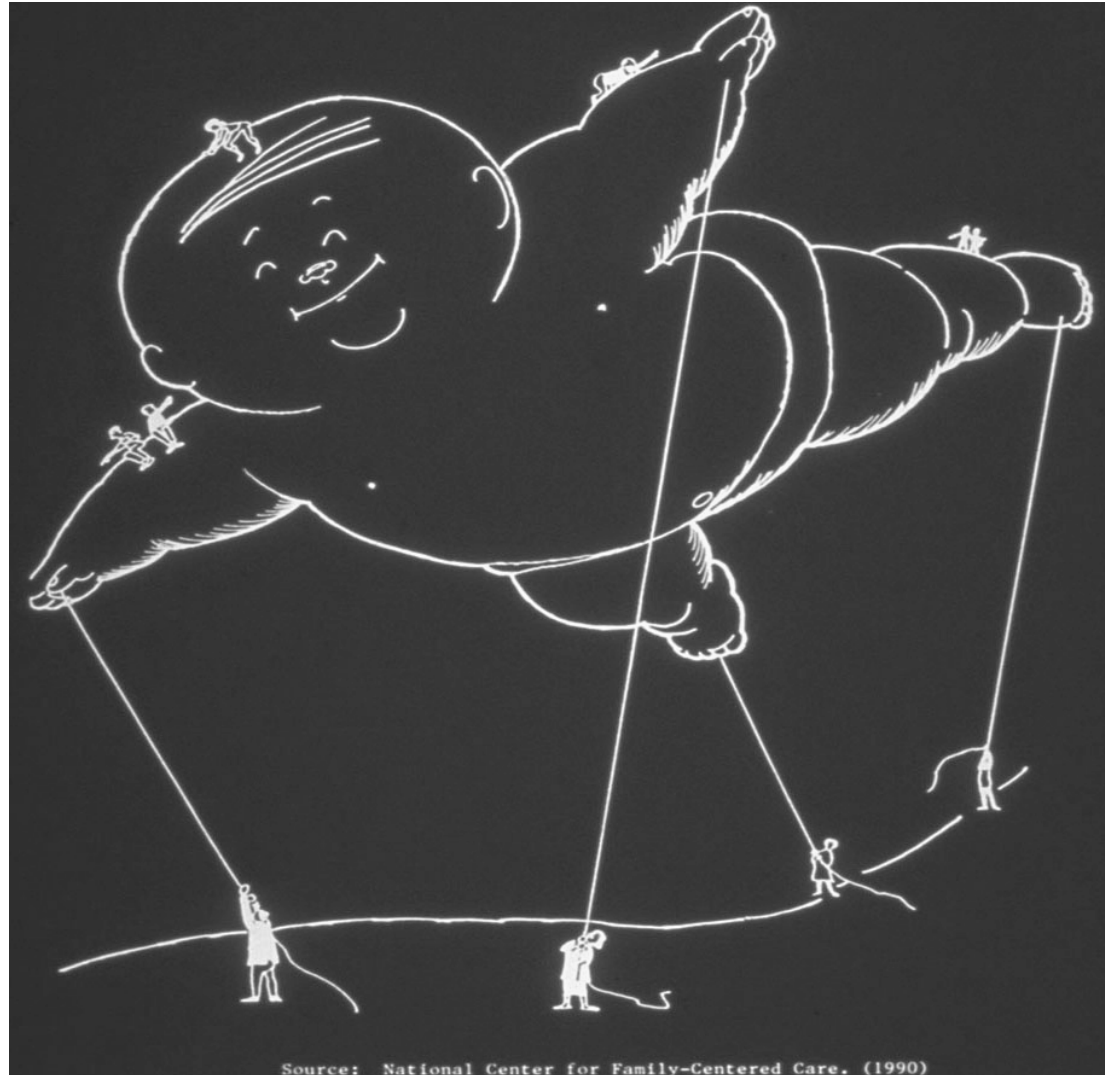
- ▼ Define the core concepts of patient- and family-centered care and how they are applied to the development of medical homes, care coordination, and palliative care.
- ▼ Describe emerging best practices for patient- and family-centered care and partnering with patients and families in health care redesign;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



System-Centered Care



Patient-Focused Care



Source: National Center for Family-Centered Care. (1990)



Patient- and Family-Centered Principles

- ▼ 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.



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.



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.

. . . 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.”

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>



Medical Home and Emerging Best Practices



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.”



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>



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?

“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.



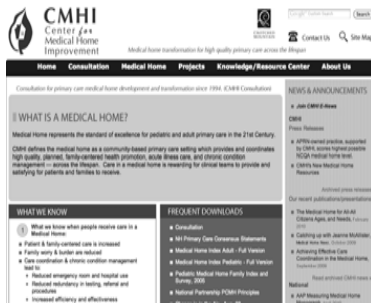
A Key Lever for Leaders . . . Putting Patients and Families on the Improvement Team

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.



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



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.



The screenshot shows the Minnesota Department of Health website. At the top, it says "Minnesota Department of Health" with the tagline "Protecting, maintaining and improving the health of all Minnesotans" and the MDH logo. Below this is a navigation bar with links for "MDH HOME", "MAIN CATEGORIES", "ABOUT US", "LIBRARY", and "NORTHSTAR", along with a search box. The main content area is titled "Health Care Homes" and includes a list of links: Home, Certification, Education and resources, Adopted rule, Outcomes measurement, Payment methodology, Consumer/family council, Capacity assessment, Learning collaborative, Events, Documents, and About. To the right of this list is the "Minnesota's Health Reform Initiative" logo, which features the word "VISION" in large letters, "MINNESOTA'S" in smaller letters above it, and "HCH Health Care Homes" to the right. Below the logo is the text "A Better State of Health".

Health Care Homes (aka Medical Homes)

A "health care home," also called a "medical home," is an approach to primary care in which primary care providers, families and patients work in partnership to improve health outcomes and quality of life for individuals with chronic health conditions and disabilities.

The development of health care homes in Minnesota is part of the ground-breaking health reform legislation passed in May 2008. The legislation includes payment to primary care providers for partnering with patients and families to provide coordination of care.



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 (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/PCPCH/PCPCHStandardsAdvisoryCommittee.shtml>



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

Oregon Health Care Quality Corporation and Peace Health Medical Group bringing about transformational change in ambulatory practices and health plans by supporting the development of sustained meaningful partnerships with patients and families at all levels of the organization.

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 Family Leadership Teams are being established at two levels – one team for the state and individual teams in 26 practices.



Patient and Family Advisors, Peace Health 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







DIABETES SELF MANAGEMENT

NAME: _____ DOB: _____

Diabetes is a very serious disease that may cause damage to the blood vessels and nerves leading to the brain, eyes, heart, kidneys, toes and feet.

You, the patient, are the most important person to manage your diabetes. Your health care team will assist you and offer support as you manage your diabetes. The following goals will help you gain and maintain diabetic control to reduce damage to your blood vessels and nerves.

Please choose goals you are willing to work on to better manage your diabetes:

	Date Set	How Ready	How Confident	Date Met
GOAL 1:  I will know my current HbA1c value My goal HbA1c is _____%				
GOAL 2:  I will check my feet daily. If I notice a sore or irritation, I will seek medical attention.				
GOAL 3: I will visit the Podiatrist yearly or as advised.				
GOAL 4:  I will take a baby aspirin or enteric-coated aspirin every day				
GOAL 5:  I currently smoke _____cigarettes per day. I will take action to stop smoking				
GOAL 6:  I will have a dilated eye exam every year or as indicated by my eye doctor. (Dr. _____)				
GOAL 7:  I will check my blood sugar as instructed and will call if the results are consistently below _____ or above _____				



- Collaborative Self-Management Support
- ◆ Information Sharing
 - ◆ Goal Setting
 - ◆ Action Plans
 - ◆ Follow-Up Support

<http://www.newhealthpartnerships.org>

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



Care Coordination and Palliative Care and Emerging Best Practices



Care Coordination in Pediatric Medical Homes

- ▼ A 3-year study involving 10 pediatric medical home practices.
- ▼ All practices had a practice-based care coordinator, and they developed and used written care plans.
- ▼ Parent partners were part of improvement teams for all practices.
- ▼ Families who were cared for in the practices reported decreased number of primary care visits, reduced specialty visits, reduced hospitalizations and length of hospital stay, fewer missed school days, and less parental worry.
- ▼ McAllister, J., Sherrieb, K., & Cooley, W. C. (2009). Improvement in the family-centered medical home enhances outcomes for children and youth with special needs, *Journal of Ambulatory Care Management*, 32:3, 188-196.



Care Coordination . . . Building on patient and family preferences

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



Harvard Medical School Boston, MA

Patients living with a life-threatening illness are teachers of first year medical students.

Students learn to elicit and value the patient's perspective; they learn about the power of listening; they learn about the kinds of supports that help patients and families manage illness; and they learn about the human experience.

Block, S. D. & Billings, J. A. (2005). Learning from the dying, *The New England Journal of Medicine*, 353(13), 1313-1315.

Harvard Medical School Boston, MA

Teaching and Learning End-of-Life Care

Physician and nurse educators acquire teaching and clinical skills through this program. Patients living with life threatening illnesses and bereaved families share their experiences in faculty moderated sessions.

Sullivan, A. M., Lakoma, M. D., Billings, J. A., Peters, A. S., Block, S. D., & the PCEP Core Faculty. (2005). Teaching and learning end-of-life care: Evaluation of a faculty development program in palliative care program, *Academic Medicine*, 80, 657-668.

Institute for Clinical Systems Improvement (ICSI)



Palliative Care Strategic Initiative

- ▼ Developing a model to integrate shared decision-making model of palliative care into routine care delivery.
- ▼ Patient/family advisors are members of the steering committee and all subcommittees for this RWJF funded project.
- ▼ Launched 5 pilots in different types of settings to determine strategies for overcoming barriers.
- ▼ Developed measures for both patient/family perspectives as well as measures for other members of the care team.
- ▼ Created training materials for ambulatory care teams to learn the philosophy and skills to integrate shared decision-making in care for patients with life-limiting illnesses.



Institute for Clinical Systems Improvement (ICSI) cont'd



Palliative Care Strategic Initiative

- ▼ ICSI's Patient Advisory Council is participating in the development of the palliative care/shared decision-making model.
- ▼ The model will be used in a statewide shared decision-making collaborative that will launch later in 2011.
- ▼ Pre-planning for the collaborative includes a patient engagement group that is creating messages for media and communications to educate and engage patients to expect and participate as partners in shared decision-making.

http://www.icsi.org/health_care_redesign_/palliative_care_46668/





Memorial Healthcare System: A Public System Focusing on Patient-and Family-Centered Care

July 7, 2010 | Volume 46

Author(s): Jennifer Edwards, Dr.P.H.

Contact: Jennifer Edwards, Health Management Associates, jedwards@healthmanagement.com

Editor(s): Martha Hostetter

Related

Publications

Carolinas Medical Center:

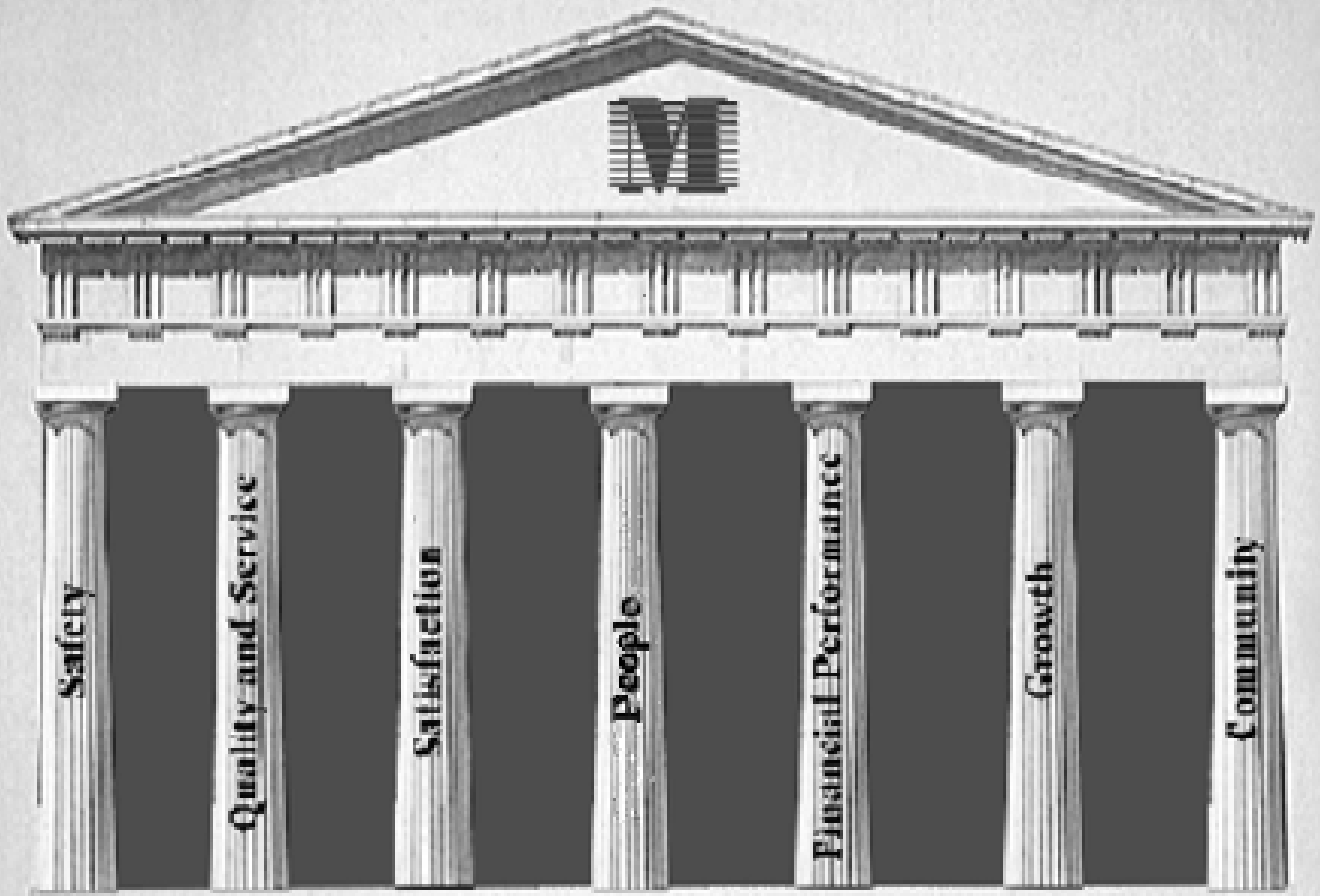
5th Largest Public Hospital in the United States

CORE MEASURES

“All four of Memorial hospitals were in top 5% of hospitals on a composite measure, and two were in the top 1% (among more than 2,000 hospitals in the analysis covering the year ending 2008.)”

<http://www.commonwealthfund.org/Content/Publications/Case-Studies/2010/Jul/Memorial-Healthcare-System.aspx>





PATIENT- and FAMILY-CENTERED CARE

The NEW Mission Statement



The Memorial Healthcare System provides safe, quality, cost-effective, patient- and family-centered care regardless of ability to pay, with the goal of improving the health of the community it serves.



Patient and Family Advisors Memorial Health System Hollywood, FL

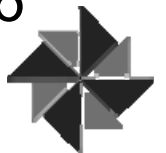
Patient and family advisors have been involved in the development of:

- ◆ The Primary Care Clinic Outpatient Pharmacy layout & process
- ◆ Adult Primary Care Clinic efficiency initiatives (scheduling, walk-ins, referrals)
- ◆ Outpatient Satisfaction Team
- ◆ Signage & Wayfinding Task Force
- ◆ Daily Med Administration Reconciliation Form
- ◆ Patient/Family Resource Center
- ◆ “E-Health” Team Website Re-Design
- ◆ Palliative Care Patient/Family Education



End-of Life Care and Palliative Care, Memorial Health System, Hollywood, FL

- ◆ A Patient and Family Advisory Council member, who experienced end of life care with her husband, participated in initial planning meetings for the Palliative Care program and continues to come to monthly update meetings. This program requires a “formal” consult from an outside provider.
- ◆ Nursing leaders have started a spin-off "end of life" committee to explore an intermediate step that could be done without a physician order by nurses (or physicians) who have had some training in palliative care and more easily begin conversations with patients and families when they wish to talk. This committee will seek advice from the Patient and Family Advisory Council as part of the planning process.
- ◆ The Advisory Council will sponsor an event in the hospital cafeteria for “National Advance Directives Day,” on April 16 and distribute copies of the “Five Wishes.”



Patient/Consumer Partnerships in Research



THE NATIONAL WORKING GROUP ON EVIDENCE-BASED HEALTH CARE

The Role of the Patient/Consumer in Establishing
a Dynamic Clinical Research Continuum:

Models of Patient/Consumer Inclusion

August 2008

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>



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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