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

Beverley H. Johnson
Improving Together: Strengthening the Consumer Voice Workshop
South Auckland, New Zealand
October 3, 2011

Our time together . . .

▼ Define core concepts of patient- and family-centered care.
▼ Discuss emerging best practices in patient- and family-centered care and for creating partnerships with patients and families.
▼ Discuss highlights from the literature that support patient- and family-centered health care.
▼ Describe ways leaders can advance the practice of patient- and family-centered care and foster effective partnerships with patients and families to enhance quality, safety, and the experience of 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.
▼ Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
▼ Collaboration among patients, families, and providers occurs in policy and program development and professional education, as well as in the delivery of care.

Patient- and Family-Centered Care Linked with Cultural and Linguistic Competency

Creating Powerful First Impressions

A welcome poster developed by patient and family advisors.

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.”

Building Momentum for Advancing the Practice of Patient- and Family-Centered Care and Creating Partnerships with Patients and Families

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.

AHA McKesson Quest for Quality Prize
. . . integrating patient- and family-centered care with quality and safety agendas.


Entire issue devoted to Patient- and Family-Centered Care
April 2010

Patients and Families as Advisors
Learning about the patient’s and family’s experience . . .

Focus groups and surveys are not enough!

Hospitals, health systems, primary care practices, and other ambulatory settings must create a variety of ways for patients and families to serve as advisors.

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.


Involving Patients and Families as Advisors

“Get started before you are ready.”

Jim Anderson
President and CEO
Cincinnati Children’s Hospital Medical Center

Recipient of the 2006 AHA McKesson Quest for Quality Prize

Integrating Patient- and Family-Centered Concepts into the Infrastructure of Health Care Organizations

- Vision/Values
- Facility Design
- Patterns of Care
- Information Sharing
- Family Support
- Charting/Documentation
- Linkages to Community
- Quality Improvement
- Human Resources
- Professional Education
- Measurement

A Leadership Profile on Advancing the Practice of Patient- and Family-Centered Care

Memorial Health System

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.)”

Leadership structure for advancing the practice of patient- and family-centered care:
- Director for Quality and Safety oversees patient- and family-centered care; she reports to the CEO for the system.
- Staff leader for patient- and family-centered care and collaborative endeavors appointed in each hospital.
- Expectation is created and re-enforced that there will be patient and family advisors for each hospital.
- Patient- and family-centered initiatives and patients and families are now a regular part of the quarterly leadership development meetings.
- Stories have become a part of the leadership culture.
- Memorial leaders have invested in leadership development for advancing 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.

Definition of Family

“MHS recognizes that the term “Family” has many meanings, and includes not only bonds created by marriage and common ancestry, but also bonds created by close friendships, commitments, shared households, shared child rearing responsibilities, and romantic attachments.”

Patient and Family Advisors

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

Daily Medication Reconciliation

Patient and family advisors were involved in the development and design of the Patient/Family Daily Medication Record.
Nurses tested the form and now share this information with patients and families on a daily basis.
Source: Commonwealth Fund
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."

Our Goals for PFCC from Patient/Family ADVISORS Memorial Health System, Hollywood, FL

We want patients and family members to be able to say "My experience of care was smooth, efficient, and met my individual needs for information, family involvement, safety and quality."

We want staff to be able to say "Because of our commitment to patient- and family-centered care, my work is easier."

Memorial Regional Hospital is the 2011 recipient of the American Hospital Association—McKesson Quest for Quality Prize.

Memorial Healthcare System

Contra Costa Regional Medical Center and Health Centers

Martinez, California

- In March 2010 a value stream mapping event was held to challenge the current state and design the ideal future state for behavioral health emergency care.
- This event brought together patients who had experienced a behavioral health emergency, family members, law enforcement, ambulance drivers, contract community agencies, and Medical Center staff.
- Four one-week long rapid cycle improvement sessions held from May through October, which involved over 800 man hours, including patients and family members, and led to meaningful changes for those in need of behavioral health services.

Contra Costa Regional Medical Center and Health Centers

Martinez, CA

- Reduction in the average number of psychiatric patients who left the ED prior to receiving care dropped by 50%;
- Saved 255 staff hours per month spent on obtaining patient medical clearances in the ED; and
- Reduction in assaults/aggressive acts reported in the ED.

Contra Costa Regional Medical Center and Health Centers, Martinez, CA
Contra Costa Regional Medical Center and Health Centers, Martinez, California

- 600 patients brought by ambulance directly to the psychiatric unit and not to the hospital’s emergency department;
- Reduced delays in getting to the psychiatric unit from the emergency department by 1000 hours;
- 14% of beds in the medical emergency department are freed up;
- The percent of patients going back into the community with a full discharge plan has gone from 50% to 90%; and
- The percent of patients being discharged on multiple psychotropic drugs has been reduced.

Contra Costa Regional Medical Center and Health Centers, Martinez, CA

Patients and families influenced the entire process—from the initial decision to focus on behavioral health, to the timing of changes, to developing ideas for rapid cycle improvements.

“There was a prevailing concern that bringing patients and families into the room would change the conversations. This is true; it has changed the conversations for the better, a centering force that grounds us in reality. We are engaging in discussions that were out of reach for our organization previously.”

Anna Roth, CEO

A Profile on Leadership for Advancing the Practice of Patient- and Family-Centered Care

University Health Systems of Eastern Carolina

- The Board and senior executive team have made an explicit commitment to patient- and family-centered care.
- The health system’s new core values include a commitment to patient and family engagement.
- The Clinical and Service Quality Pillar reinforces this commitment with the words: “Partner with patients and families to achieve safe, high quality care and exceptional experiences.”
- A Vice President at the Corporate level leads the Office of Patient/Family Experience.
- Within this office, there is an Administrator that serves as a staff liaison for collaborative endeavors and builds synergy with all efforts to improve the patient experience.

University Health Systems of Eastern Carolina, Greenville, NC

Changing the Concept of Families as Visitors

Leadership . . .

Changing Nursing Practice

Pitt County Memorial Hospital
Greenville, NC
University Health Systems of Eastern Carolina, Greenville, NC

Patient and family advisors serve with operations leaders on University Health Systems Coordinating Groups (UCGs). UCGs provide guidance, analysis, and/or recommendations on standardization, quality of care, regulatory compliance, cost and effectiveness, and other matters that improve performance system wide.

Advisors participate in the development, implementation and evaluation of the UHS Corporate Quality Long-Range plan. This plan drives the patient safety, quality improvement, and patient experience work for every UHS entity.

Patient/family advisor serves on UHS Board of Trustees Quality Improvement Committee.

Developing advisory councils for home health and hospice.

University Health Systems of Eastern Carolina, Greenville, NC

▼ In 2011, ranked 4th nationally in patient satisfaction among all academic medical centers in University HealthSystem Consortium.

▼ 50% reduction in hospital acquired infections in past two years.

▼ 73% reduction in serious safety events since 2007.

▼ RN turnover decreased from 15.26% in 2008 to 5.18% in 2011.

▼ Results of 2011 employee opinion survey indicated PFCC as strength at the unit-level and at the organization-level.

The Impact of Partnering with Patients and Families at MCGHealth, Augusta, GA

MCG Health System, Augusta, GA
A Model Patient- and Family-Centered Neuroscience Center of Excellence

MCG Values applied to a unit-based pledge developed through a collaborative process.
Patient encouraged to be an active participant in care and decision-making.

Families no longer seen as visitors.

MCG Neuroscience Results 2004-2010

- Patient Satisfaction – 10th to above 90th percentile.
- Length of stay decreased – 50% in Neurosurgery.
- Discharges (volume) increased 15.5%.
- Capacity for continuous improvement.
- Staff vacancy rate – 7.5% to 0%; 5-7 RN’s on waiting list.
- Change in perceptions of the unit by doctors, staff, and house staff.
- Staff protects the new culture.

Currently 7 Inpatient Neuroscience Patient/Family Advisors and 7 Outpatient Neuroscience Patient/Family Advisors

MCG Health, Augusta, GA
Overview of Malpractice Expenses

Changing the Culture of an Organization . . .

A Journey, not a Destination

Partnering with Patients and Families is Key
Recognizing Driving Forces

- **System-Centered Driving Force:**
  The priorities of the system and those who work within it drive the delivery of health care.

- **Patient-Focused Driving Force:**
  The patient is the focus or unit of care. Interventions are done to and for him/her, instead of with the patient. The patient is not viewed within the context of family or community.

- **Family-Focused Driving Force:**
  While the family is the focus or the unit of care, interventions are done to and for them, instead of with them.

- **Patient- and Family-Centered Driving Force:**
  The priorities and choices of patients and their families drive the delivery of health care.

Discussion of Scenario #1

Highlights of Best Practices
Supporting Family Presence and Participation
New Critical Care Tower
Vanderbilt University Medical Center

Thank you for making your choice for your health care.

We Welcome You

Family presence and support during the intense care phase of a loved one's illness is very important. We encourage your presence and invite you to take an active role during this time.

Developed with Patient and Family Advisors

Trauma Surgery Rounds with the family in an Open Bay Unit.

A Fundamental Shift in Practice . . .
Family-Centered Rounds . . . Supporting Patient and Family Presence and Participation

http://www.vanderbilthealth.com/traumasurvivors/

Emory Healthcare, Atlanta, Georgia
Bedside Nurse Change of Shift Report

Nurse change of shift report is now conducted at the bedside with patients and families across all shifts in all four of Emory’s hospitals. In less than six months of implementation, positive gains have been seen in patient satisfaction scores, and nursing morale is high.

Patient and family advisors collaborate with staff in conducting the education for frontline staff for this change in practice.


Emory Healthcare, Atlanta, GA
Bedside Nurse Change of Shift Report
Perham Memorial Hospital

Transition Planning with the patient and family and hospital and community providers

http://www.ihi.org/IHI/Topics/MedicalSurgicalCare/MedicalSurgicalCareGeneral/Tools/TCABHowToGuideTransitionHomeforHF.htm

Sharing Personal and Professional Stories

“Facts bring us to knowledge,
Stories bring us to wisdom.”
Rachel Remen

Partnering with Patients and Families
New Ways of Working and Practical Strategies for Success

Why involve patients, residents, and families as advisors?

- Bring important perspectives.
- Teach how systems really work.
- Keep staff honest and grounded in reality.
- Provide timely feedback and ideas.
- Inspire and energize staff.
- Lessen the burden on staff to fix the problems... staff do not have to have all the answers.
- Bring connections with the community.
- Offer an opportunity to “give back.”
Mental Barriers - Challenges for Leaders

- We don’t have time for this.
- Patients and residents will hear the negatives about our organization.
- We don’t want to air our dirty laundry.
- This is nice to talk about, but…
- Patients/residents and families just don’t understand our system.
- They will want things that cost too much and we’ll have to tell them “no.”
- We are not a hotel; we are here to save lives.
- We need to be better organized.

Cincinnati Children’s Hospital Medical Center
Cincinnati, OH

- Families are integral members of QI teams.
- There is a hospital-wide Family Advisory Council.
- Rehabilitation programs are designed to respect the patients’ and families’ unique values, needs and cultural differences. Patients and families are integral members of the care team and their active participation is supported.
- A family advisor is a member of the Board of Trustees.
- Families participated in the design of a patient safety tool. Nurses ask key questions of families about any safety concerns that they may have for their child at admission, discharge, and when they call into the unit.

PICU-Based Family Advocacy Board
Stony Brook University Hospital, Stony Brook, NY

- Designed and distributed parental survival guide and posters in English and Spanish.
- Organized and facilitated PICU family coffee hours.
- Created voice mail hotline for families for support issues.
- Participated on PICU Performance Improvement Team.
- Assisted in changes to include families in nurse bedside change of shift report, improve transition from ED to PICU, and developed an education module on communicating with families for staff.
- Participated in hospital-wide medication safety retreat.


NICQ Series—Vermont Oxford Network

Since 1998, national quality improvement collaboratives have been working to advance the practice of family-centered care within Newborn Intensive Care.

53 NICUs participated in the 2009-2010 collaborative and the majority have family advisors as some of their QI teams. In addition, a parent serves on the 6-member NICQ Advisory Board for the collaborative and one of the faculty for the collaborative is a parent who has had family experience in the NICU. In 2011, QI teams will be co-led by family advisors.

Patient and family advisors at Ocean Park Health Center, San Francisco, CA

Patient and family advisors planned the “walk and talk series.”
The Patient Advisory Council members have been enthusiastic and interested in improving care of patients and outreaching to the community.

Each time I attend their meetings, their energy and passion revitalize me and help me to remember the reasons for which we are all here: to serve our patients.

Lisa Golden, MD, Medical Director
Ocean Park Health Center
San Francisco, CA

Patient and Family Advisor Participation in Cardiac Clinic Design

A collaborative design planning process saves dollars.

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

Patient and Family Advisors Guide Change in Teamwork Training for Ambulatory Patients

- Original plan was for one-hour training sessions on communication techniques.
- Campaign rather than education or research.
- Focus on hazards rather than skills.
  - Wrong chemo, last-minute change, hand hygiene.
- Bringing messages to the patient.
- Empowerment without obligation.
  - “You CAN… check, ask, notify.”


Dana-Farber Cancer Institute, Boston, MA

Institute for Clinical Systems Improvement (ICSI)

Palliative Care RWJF funded Strategic Initiative

ICSI’s Patient Advisory Council is participating in the development of the palliative care/shared decision-making model.

Patient/family advisors are members of the steering committee and all subcommittees for this project.

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/
High Plains Research Network (HPRN) Community Advisory Council, Colorado

- A Network of 12 rural hospitals and clinics in Colorado’s northeast region.
- Since 2003, the Community Advisory Council has worked with the Network and participated in "research design, qualitative analysis, interpretation of results, and dissemination of findings" (Westfall, 2006, p. 1).
- The Council has 12-18 members — includes farmers, ranchers, school teachers, even high school students.
- The Council meets 3-5 times a year in person; they have regular telephone calls focused on a specific topic every 7-10 days and lasting no more than 30 minutes; they conduct some work through email exchange.

High Plains Research Network (HPRN) Community Advisory Council, Colorado (cont’d)

- An all day “boot camp” is held prior to working on a project. Projects have included:
  - Colon cancer prevention;
  - Asthma awareness and management;
  - Under-insurance;
  - Obesity; and
  - Patient-centered medical home.
- "The Community Advisory Council has made our research ten times better, much more relevant to the communities we serve. In addition, it’s a lot of fun to work with the Community Advisory Council." Jack Westfall, MD, MPH, personal correspondence.

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-1972-4D20-C8CF5F3E1B568572
Families as Full Research Partners — King County Blended Funding Project

Children's Mental Health Program


Strategies for Success

Qualities and Skills of Successful Patient and Family Advisors

- The ability to share personal experiences in ways that others can learn from.
- The ability to see the bigger picture.
- Interested in more than one agenda issue.
- The ability to listen and hear other points of view.
- The ability to connect with people.
- A sense of humor.
- Representative of the patients and families served by the hospital and clinics.

Recruiting Patient and Family Advisors

- Ask staff and physicians for suggestions.
- Contact support groups and community organizations such as Rotary, Kiwanis, fire stations, and religious organizations.
- Ask current patient and family advisors.
- Call or send a mailing to patients and families.
- Ask patients/families during a clinic visit or during a hospital stay when appropriate.
- Post signs/brochures on bulletin boards in waiting areas, corridors, and lobbies.
- Place notices in the clinic’s, hospital’s, or nursing home’s publications, websites, and TV systems.
- Post information on Twitter and Facebook.
Fostering a Successful Beginning for Patient and Family Advisors

- Use of Volunteer Department
  - Background Checks.
  - Health Assessment.
  - Portion of Hospital Orientation.
  - Safety-Security Protocols
  - Infection Control
  - Confidentiality and Privacy
  - HIPAA Training
  - Signing Confidentiality Statement
  - Maintain Volunteer Advisor Hours.
  - Recognition Efforts.
  - Annual Compliance for Joint Commission.

Fostering a Successful Beginning: Orienting Patient and Family Advisors

- Logistical Details
  - What to wear
  - Where to find food and drink
  - Location of bathrooms
  - Transportation and parking
  - Child care
  - Stipends/Reimbursements
Fostering a Successful Beginning: Orienting Patient and Family Advisors

- Mission, Values, Priorities of the Unit, Clinic or Hospital
- Speaking the Language–Medical Jargon 101
- Who’s Who in the Organization
- Hospital/Clinic Tour
- “Day in the Life”
- Council Meeting Attendance Expectations
- Roles and Responsibilities on the Council
  - Patients, Families, Staff

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

What if–not a good fit …

- Review skills and attributes.
- Is there another advisory role?
- Keep name on a list.
- Be clear and honest.

Fostering a Successful Beginning: Orienting Staff

- Serve as a connection between other staff and the advisory group.
  - Assist in communicating activities of the advisory group to other staff and leaders.
  - Be a patient- and family-centered “champion.”

Fostering a Successful Beginning: Orienting Staff (cont’d)

- Explain how staff should be involved.
  - The importance of listening.
  - Effective approaches to meeting facilitation.
- Be open to questions and challenges.
- Try not to be defensive.
  - Respond/explain without being defensive.
  - Defensiveness usually has a negative effect.
Keeping Councils Active, Growing, and Successful

Review Council Structure
- Size—too big or too small?
- Have officers and sub-committees been identified?
- Terms of Membership?
  - Staggered terms?
  - Opportunities to serve before and after the Council?
  - Staff to patient/family ratio 1:3?

 Conducting Effective Meetings
- Spend extra time on introductions.
- Begin some meetings with patient and family stories.
- Discuss the concept of collaboration explicitly at the beginning of a new endeavor and assess how it is working at the end of meetings.
- Stay on the agenda.
- Avoid using jargon.
- Encourage the participation of patient and family advisors, validating their role as committee members.
- Plan proactively for challenging situations.
- Establish ground rules for conducting meetings.

What keeps advisory councils active, growing, and successful?
- Advisors feel they are being listened to.
  - If something cannot be done, they are told why.
- Advisors feel they are making a difference. They are involved in specific projects.
- Staff and other patients and families are aware of the council and its activities.
- Skills and talents of advisors match the needs of the council and its work.

What keeps advisory councils active, growing, and successful?
- Meetings are enjoyable and productive.
- Agendas are not too long.
- Meetings are of substance and value.
- Leaders recognize and value the contributions.
- Genuine openness and transparency exists.
- Organization celebrates successes.
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.

University of Michigan Health System Quality Measures

Using the STEEP Framework, health care should be patient-centered:
- Patients’ ratings of care.
- Patient complaint and commendation trends.
- % compliance with advance directives.
- Health Education Resource Center statistics.
- # of patients and family members on health system committees and advisory groups.
- Interpreter services:
  - # of requests.
  - # of languages provided.


The Roles of Leaders

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.
Discussion of Scenario #2

Exploration of Strategies to Consider in Establishing a Pilot Site

The Magic Wand

References and Resources


References and Resources (cont’d)


References and Resources (cont’d)

References and Resources (cont’d)

- Institute for Patient- and Family-Centered Care: www.ipfcc.org.

References and Resources (cont’d)

- Patient-Centered Medical Home Resource Center http://www.pcmhahrq.gov/portal/server.pt/community/pchm_home/7495

References and Resources (cont’d)


References and Resources (cont’d)