

Patient- and Family-Centered Care

From Principles to Practice

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www.familycenteredcare.org

Learning Objectives

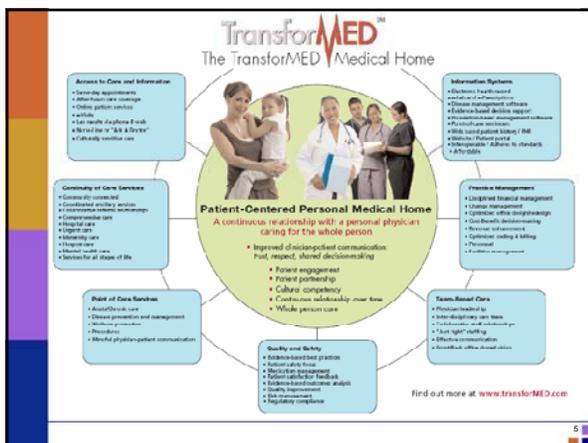
- Be familiar with the principles of patient- and family-centered care in the Medical Home
- Know the tips that turn these principles into practice

Medical Home

Medical Home

Medical Home- Joint Principles

AAP, AAP, ACP, AOA (3/5/07)



What Is a Medical Home? (AAP)

- Approach to providing health care services in high-quality, comprehensive, and cost-effective manner
- Provision of care through primary care physician in partnership with other allied health care professionals and the family
- Acts in the child's best interest to achieve maximum family potential

What Is a Medical Home? (AAFP)

The American Academy of Family Physicians believes that everyone should have a *personal medical home* that serves as the focal point through which all individuals—regardless of age, sex, race, or socioeconomic status—receive acute, chronic, and preventive medical services. Through an on-going relationship with a family physician in their medical home, patients can be assured of care that is not only accessible but also accountable, comprehensive, integrated, patient-centered, safe, scientifically valid, and satisfying to both patients and their physicians.

Medical Home

Medical Home

Medical Home Common Elements

- Accessible
- Family-centered
- Continuous
- Comprehensive
- Coordinated
- Compassionate
- Culturally effective

and for which the Primary Care Physician shares responsibility

Institute of Medicine The National Health Care Quality Report

Institute of Medicine Crossing the Quality Chasm: A New Health System for the 21st Century

Rules for Health Care in the 21st Century

The National Health Care Quality Report

- Care based on continuous healing relationships
- Care customized according to patient needs and values
- Patient is the source of control
- Knowledge shared, information flows freely
- Decision making is evidence-based

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Rules for Health Care in the 21st Century

The National Health Care Quality Report

- Safety is a system property
- Transparency is necessary
- Needs are anticipated
- Waste is continuously decreased
- Cooperation among clinicians is a priority

Crossing the Quality Chasm IOM, March 2001 14

Patient- and family-centered care provides the framework and strategies for improving quality, safety, and the experience of care.

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American Academy of Pediatrics

(September 2003; Reaffirmed September 2007)



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American Board of Internal Medicine (ABIM) Foundation

2008 Invitational Forum

Eight patient and family advisors participated in deliberations along with clinicians, educators, and other health care leaders.



www.abimfoundation.org

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ABIM Foundation

2008 Invitational Forum

In Kimball Lecture, Don Berwick outlined key aspects of patient- and family-centered care:

- No visiting restrictions
- Patient and family participation in rounds
- Medical records belong to the patient
- Shared decision-making technologies
- Patients and families participate in design of health care processes and services

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Press Release February 2007 Society of Critical Care Medicine
The Intensive Care Professionals

- Evidence-Based Clinical Practice Guidelines for incorporating families into decision-making and care for ICU patients
- Open visitation (24/7) in pediatric and newborn intensive care and supporting family participation in rounds and presence for resuscitation
- Open visitation in adult intensive care is flexible for patients and families and determined individually

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Debunking the myth that families are visitors

- Families are not VISITORS
- Families are allies for quality and safety
- Families are the constant across the transitions in health care
- Family presence and participation during rounds and nurse change of shift report can enhance quality and safety

JAMA
Restricted Visiting Hours in ICUs
Time to Change
COMMENTARY
Donald M. Berwick, MD, MPH, DBCP
Steve Longel, BA

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American Heart Association

Health Care Providers should offer the opportunity to family members to be present during resuscitation whenever possible

American Heart Association Scientific Statement: International Guidelines 2000 for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care: A Consensus on Science
Helm, M. A. (2005). Family presence during resuscitation: A critical review of the literature. *American Journal of Critical Care*, 14(6), 494-514.

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American Academy of Orthopaedic Surgeons (AAOS)

Defines Patient-Centered Care as:

a partnership among the orthopaedic surgeon, an informed and respected patient (and family), and a coordinated health care team



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Goals of the AAOS Patient-Centered Care Campaign

- Residents in all 150 orthopaedic residency training programs take the AAOS course in Patient-Centered Communication by 2008
- 25% of AAOS members also complete the course by 2008

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American Academy of Orthopaedic Surgeons (AAOS)

- Each member is asked to sign a pledge for how he or she will work with patients and families and to display this pledge in their offices

For further information: Fairley, F. A. & Weinstein, S. L. (August 2006). The case for patient-centered care in orthopaedics. *Journal of the American Academy of Orthopaedic Surgeons*, 14(8), 447-451.

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Accreditation Council for Graduate Medical Education

- Patient Care
- Medical Knowledge
- Practice-Based Learning and Improvement
- Interpersonal and Communication Skills
- Professionalism
- Systems-Based Practice



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National Priorities Partnership

"diverse group of national organizations representing those who receive, pay for, deliver and evaluate health care"

- AARP
- AFL-CIO
- AHRQ
- America's Health Insurance Plans
- Am Brd of Medical Specialties
- American Nurses Association
- CDC
- CMS
- Consumers Union
- Institute for Healthcare Improvement
- Institute of Medicine
- The Joint Commission
- Leapfrog Group
- National Association of Community Health Centers
- National Business Group on Health
- National Committee for Quality Assurance
- National Governors Association
- National Institutes of Health
- National Quality Forum
- Physician Consortium for Performance Improvement
- Quality Alliance Steering Committee
- The U.S. Chamber of Commerce

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National Priorities Partnership

- Patient and family engagement
 - to provide patient-centered, effective care
- Population health
 - to bring greater focus on wellness and prevention starting in our communities
- Safety
 - to improve reliability and eliminate errors wherever and whenever possible

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National Priorities Partnership

www.rwjf.org/qualityequality/product.jsp?id=33971

- Care coordination, to provide patient-centered, high-value care
- Palliative and end-of-life care, to guarantee appropriate and compassionate care for patients with advanced illnesses
- Overuse, to remove waste, encourage appropriate use, and achieve effective, affordable care

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Quality is more than technical quality.

The patient's and family's experience can be a driver for quality improvement.

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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

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Patient- and Family-Centered Principles

- 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

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What is a Family?

Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire of mutual support. A family is a culture unto itself., with different values and a unique way of realizing its dream; together, our families become the source of our rich cultural heritage and spiritual diversity. Our families create neighborhoods, communities, states and nations.

-Task Force on Young Children and Families, New Mexico Legislature

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What is a Family?

A family is a group of people who make an irrational commitment to each other's well being to the point of making each other crazy.

-Uri Bronfenbrenner

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Recognizing The Driving Forces

- System-Centered Driving Force
- Patient-Focused Driving Force
- Family-Focused Driving Force
- Patient- and Family- Centered Driving Force

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System-Centered Driving Force

The priorities of the system and those who work within it drive the delivery of health care.

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System-Centered Driving Force

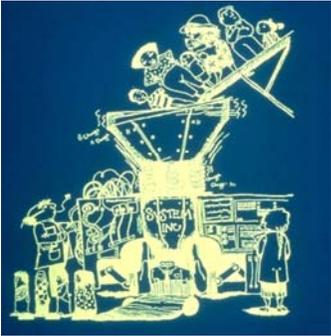


Image source: National Center for Family-Centered Care (1990)

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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.

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Patient-Focused Driving Force



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Image source: National Center for Family-Centered Care (1990)

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.

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Family-Focused Driving Force



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Image source: National Center for Family-Centered Care (1990)

Patient- and Family-Centered Driving Force

The priorities and choices of patients and their families drive the delivery of health care.

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Patient- and family-centered care is working **with** patients and families, rather than doing **to** or **for** them.

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"To write prescriptions is easy; but to come to an understanding with people is hard."

- Franz Kafka
"A Country Doctor" (1916)

Collaboration

"Collaboration means that no one interest group is always right. It means taking what you think, and what I think, and what someone else thinks, and coming up with something that works for everyone."

- Bev McConnell Crider
From *Essential Allies: Families as Advisors*

Collaboration

An unnatural act between non-consenting adults.

- Elements of Collaboration**
- Mutual respect for skills and knowledge
 - Honest and clear communication
 - Understanding and empathy
 - Mutually agreed upon goals
 - Shared planning and decision making

- Elements of Collaboration**
- Open and two-way sharing of information
 - Accessibility and responsiveness
 - Joint evaluation of progress
 - Absence of labeling and blaming

Family/Professional Collaboration

At all Levels of Health Care

- In the care for an individual patient
- In program planning and evaluation
- At the policy level

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Barriers to Collaboration

- Attitudes & perceptions about each other
- Past experiences
- Cultural differences
- Socioeconomic and educational influences
- Lack of skills
- Lack of logistical & administrative support
- Different purposes or agendas

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What Patients and Families Want to Know from Clinicians

- What is the problem?
- How can it be diagnosed and treated?

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What Patients and Families Want to Know from Clinicians

- How can I contribute to the process to enhance the quality and safety of care?
 - When/where/how will we communicate?
 - Will you listen?
- What does this mean for my family's life?
 - What is the plan?
 - How will we best continue care at home?

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Communication

- Patient- and family-centered care is not just "being nice". It is a *direct and intentional effort to unequivocally communicate to patients that they are viewed as distinct and valuable individuals with a family and place in the community.*
- The individuality of each patient and family is acknowledged.
- Relationships between patients, families, and providers are *essential alliances and partnerships* with each bringing expertise to decision-making.

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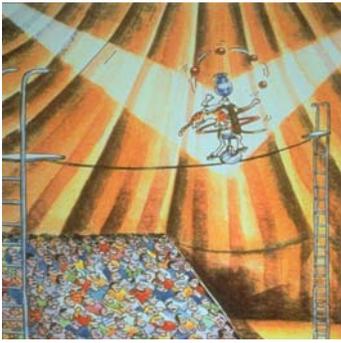
"I didn't want to make the wrong mistake."

-Yogi Berra

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High above the hushed crowd, Rex tried to remain focused. Still, he couldn't shake one nagging thought:

He was an old dog and this was a new trick.



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Patient- and Family-Centered Care Rules to Live By

- Attitude is everything
- Values determine outcomes
- All families have strengths
- Sensitivity does not mean psychoanalysis

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Patient- and Family-Centered Care Rules to Live By

- Case management is not the answer
- Patients and families are the experts on the experience of being service consumers
- The person with the most flexibility will be the catalytic element in the system

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Patient- and Family-Centered Care Tricks of the Trade

- Treat each person as an individual
- Respect patient and family knowledge about their own health needs
- Meet patients and families at their models of the world
- Negotiate your role and relationship (areas of responsibility)

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Patient- and Family-Centered Care Tricks of the Trade

- Share knowledge and information
- Avoid psychological labeling
- Assist in problem solving
- Teach choice
- Honor natural supports

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Patient- and Family-Centered Care Tricks of the Trade

- Say "I don't know," when you don't know
- Develop roles for patient and family consultants
- Consider functional issues in a gradual but systematic way
- Create alliances with other professionals at a personal level

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Patient- and Family-Centered Care

Tricks of the Trade

- Make the primary care-specialist relationship work
- Make sure that your staff knows about special needs
- Anticipate cross coverage
- Develop financial creativity
- Make talk time available

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“To practice medicine with good spirit does not mean to be in a place where there is no noise, trouble, or hard work . . .

It means to bring your calm and loving heart right into the midst of it.”

- Rachel Naomi Remin, M.D.
(adapted from unknown author)
Institute for the Study of Health and Disease

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Ask a Question

 **Viewing online?**

- Click on the chat icon above
- Question emailed to Training Team
- Questions answered by expert on topic
- Response within 2-3 weeks



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Acknowledgements

- CDC-Research Topics of Interest
- WI Medical Home Webcast Series
- Waisman Center
- WI CYSHCN Program

 Waisman Center
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 Children and Youth with Special Health Care Needs

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