Collaboration with Patients and Families in Clinical Practice

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"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



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.
- 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.



"You will never develop true patient- and family-centered care by using patients and families merely as focus groups".

Lawrence Schulman, M.D.
Physician-in-Chief
Dana-Farber Cancer Center



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.



What Patients and Families Want to Know From Clinicians

• What is the problem?

How can it be diagnosed and treated?



What Patients and Families Want to Know From Clinicians

What is the problem?

How can it be diagnosed and treated?

- 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?



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.

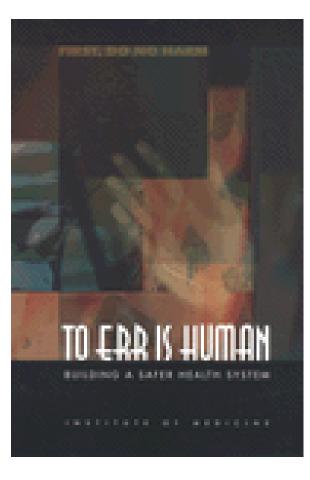
The individuality of each patient and family is acknowledged.

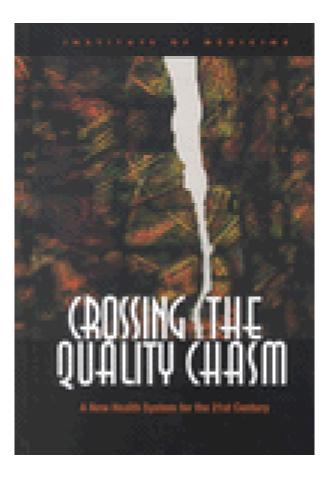
Relationships between patients, families, and providers are *essential alliances* and *partnerships* with each bringing expertise to decision-making.



Institute of Medicine

- The National Health Care Quality Report







Rules for Health Care in the 21st Century—The National Health Care Quality Report

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



Rules for Health Care in the 21st Century—The National Health Care Quality Report (cont'd)

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

Crossing the the Quality Chasm: A New Health Care System for the 21st Century Institute of Medicine, March 2001



Classification Matrix for Measures for the National Health Care Quality Report

Components of Health Care Quality

	Safety	Effectiveness	Patient Centeredness	Timeliness
Staying healthy				
Getting better				
Living with illness or disability				
Coping with the end-of-life				

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

> Institute of Medicine March 2001



Patient Centeredness: A Definition

National Health Care Quality Report

Patient centeredness refers to health care that establishes a partnership among practitioners, patients, and their families (when appropriate) to ensure that decisions respect patients' wants, needs, and preferences and that patients have the education and support they require to make decisions and participate in their own care.

Crossing the Quality Chasm: A New Health System for the 21st Century. Institute of Medicine, March 2001.



Patient- and Family-Centered Principles

- People are treated with respect and dignity.
- Health care providers communicate and share complete and unbiased information with families in ways that are affirming and useful.
- Individuals and families build on their strengths by participating in experiences that enhance control and independence.
- Collaboration among 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 Rules to Live By

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



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



Patient- and Family-Centered Care Tricks of the Trade (cont'd)

- 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.
- 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.

