Better Together

Partnering with Families

INSTITUTE FOR PATIENT- AND FAMILY-CENTERED CARE

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Family Presence: Why, What, & How?

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Session Objectives

- Discuss rationale for recognizing families as partners in care, rather than "visitors"
- Define aspects of family presence
- Review key strategies used by hospitals in changing policy & practice
- Understand the range of resources in IPFCC's ***Better Together*** Toolkit
- Identify initial strategies for change

Session Outline

- Introduction: Establishing the need for change
- Understanding family presence
- Reviewing key strategies for change in hospitals
- Resources for change: ***Better Together*** on the IPFCC web
- Defining initial action steps for change
- Questions

From the history that so often generates the diagnosis

To the treatment that is the basis of care or cure,

Active participation of patients and families is essential to optimal outcomes.

Aronson, 2013

Core Concepts of Patient- and Family-Centered Care

Respect and dignity: Health care practitioners listen to and honor patient and family perspectives and choices. Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.

Information Sharing: Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful. Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.

Core Concepts of Patient- and Family-Centered Care

Participation: Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.

Collaboration: Patients and families are also included on an institution-wide basis. Health care leaders collaborate with patients and families in policy and program development, implementation, and evaluation; in health care facility design; and in professional education, as well as in the delivery of care.

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

Data
Presence & Participation:

- Enhance patient & family experience of care
- Improve management of chronic & acute illnesses
- Strengthen continuity
- Prevent readmissions
- Provide cost savings

Traditional Beliefs

". . . much of what takes place in the way of
specific policies and practices . . .
across the country
is based on tradition
rather than science."

H. Markel, 2008

Beliefs and Concerns

- Confidentiality
- Infection control
- Patient safety
- Security
- Needs of patients & families
- Impact on staff

Partners and allies . . .

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Partnership Means:

Patients define their "family" and other "partners in care" – and how they will be involved

Families and other partners in care are encouraged and supported to be **present** and **participate** in care, care planning, and decision-making – according to patient preferences

What is “Family”

- The word “family” refers to two or more persons who are related in any way- biologically, legally, or emotionally.

- Patients and families define their families.

Aspects of Family Presence

- 24/7 access
- During bedside change of shift
- During physician rounding
- During resuscitation
- Choice of patient & family

Strategies for Change
Advice from Leaders

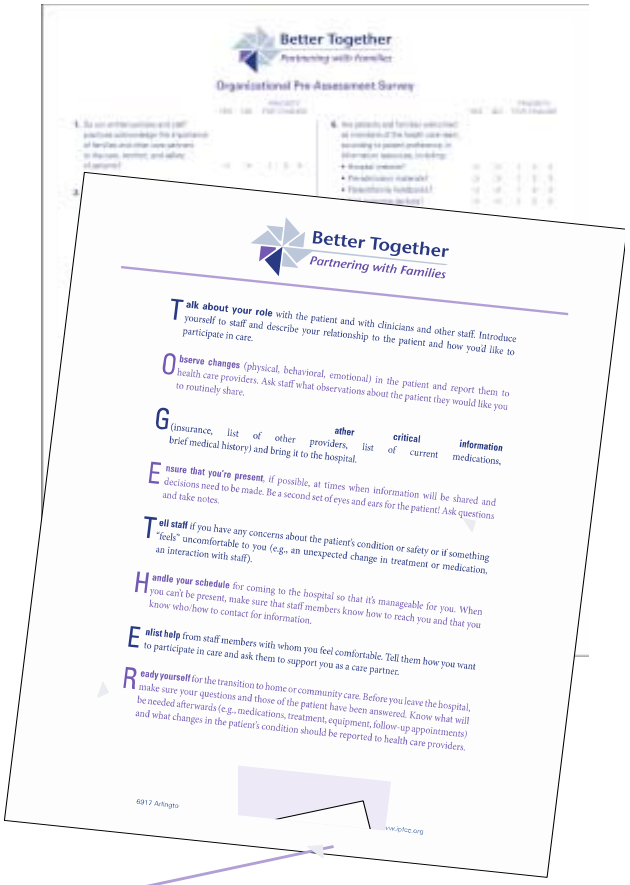
- Our commitment to patient- and family-centered care affects everything we do.
- A defining moment occurred when a hospital employee and her family shared their story with senior leaders, describing their experience of being treated as “visitors.”
- It helps that the CEO is strongly on board.

Strategies for Change
Advice from Leaders

- Work groups were convened with patients, families, and staff from every department.
- Leadership listened intently and engaged in dialogue about the concerns of staff.
- Each department mapped out the steps needed for a successful roll out, including what training was necessary.

Better Together: Toolkit

- Strategies for changing policies
- Strategies for educating staff
- Guides for families and staff
- Videos
- Media resources



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Organizational Self-Assessment

This organizational self-assessment provides an opportunity for a hospital to assess current policies and practices as part of a pro
the concept of families as "visitors" to welcoming families as essential members of the care team, according to patient preferen
determine initial priorities and action steps to begin the process of change and improvement. It can also be used to track progres

The name of the hospital where I work is: _____

	YES	NO	PRIORITY FOR CHANGE
1. Does our hospital acknowledge the importance of families and other care partners to the care, comfort, and safety of patients in:			
• Written policies?	○	○	1 2 3
• Staff practices?	○	○	1 2 3
• Website?	○	○	1 2 3
2. Do our hospital's written policies refer to families and other care partners as essential members of the health care team and not as "visitors?"	○	○	1 2 3
3. Does our hospital encourage patients to define their family or other care partner who will be involved in care and decision-making through:			
• Written policies?	○	○	1 2 3
• Staff practices?	○	○	1 2 3
• Documentation systems?	○	○	1 2 3
4. Does our hospital encourage patients to identify their preferences for how family members and other care partners will be involved in care, care planning, and decision-making in:			
• Written policies?	○	○	1 2 3
• Staff practices?	○	○	1 2 3
• Documentation systems?	○	○	1 2 3
5. Does the hospital's family presence policy welcome siblings and children of all ages according to patient and family preferences?	○	○	1 2 3

	YES
6. Does our hospital make a distinction between families and other care partners AND visitors (i.e., friends, colleagues, or distant relatives who may wish to visit) in:	
• Written policies?	○
• Website?	○
• Patient information materials?	○
• Staff practices?	○
7. Do our staff practices welcome families 24 hours a day and during:	
• Rounds?	○
• Shift changes?	○
• Codes or other emergency situations?	○
8. Are patients and families welcomed as members of the health care team in:	
• Pre-admission materials?	○
• Patient/family handbooks?	○
• Unit welcome packets?	○
9. Does our hospital's website:	
• Refer to families and other care partners as essential members of the health care team and not as "visitors?"	○
• Convey the message that families and other care partners are welcome 24 hours a day and 7 days a week?	○
• Provide useful information that encourages families and other care partners to participate in the care of their loved ones?	○

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"Facts and Figures"
About Family Presence and Participation

Restrictive visiting policies are often based on long-held beliefs that the presence and participation of families interferes with care, exhausts the patient, is a burden to families, or spreads infection. These are myths and misperceptions. **There is no current evidence to support those beliefs.**

Current Realities

- Social Isolation is a risk factor . . . Research is clear that isolating patients at their most vulnerable times from the people who know them best places them at risk for medical error, emotional harm, inconsistencies in care, and costly unnecessary care.[1,2]
- Research indicates that for many older patients, hospitalization for acute or critical illness is associated with reduced cognitive function.[3] Families and other "partners in care" are more keenly aware of any change in cognitive function than hospital staff and therefore are a valuable resource during hospitalization.
- In a study of 606 hospitals in the U.S., 76.4% had restrictive hospital visiting policies and 89.6% of the ICUs had restrictions.[4]

> *"I was scared that I was going to die because of my previous reaction to Fentanyl. My husband knew, my mother knew—but they weren't there. That terrifying situation happened because the hospital's rules wouldn't allow my family to stay with me."*
>
> — A Patient's Story

- The majority of U.S. hospital ICU policies restrict family visiting.[5]
- In New York State, 26% of acute care hospitals have statements on their websites which are contrary to state and federal policies regarding patients' right to choose visitors.[6]
- In a 2014 Health Research & Educational Trust (HRET) survey of U.S. hospitals, about 58% of hospitals report that they have a policy or guidelines that exist across all units in the hospital that facilitate unrestricted access to the patient by families or partners in care, according to patient preference.[7]
- A 2014 U.S. Health and Human Services report shows positive effects of the recent national focus on quality and safety for Medicare fee-for-service beneficiaries. The readmission rate dropped to 17.5 percent over six years and the rate of harm dropped 9 percent in two years. While these are positive trends, there is still much work to be do to improve care transitions and patient safety.[8]

Evidence to Guide Change in Practice

- Family presence in adult critical care:
  - Decreases anxiety for patients and families.
  - Increases satisfaction for patients and families.[5]
- ICU nurses gain a more personalized view of their patients through family members and believe that families provide an essential source of emotional support to patients which has positive effects on physiological and psychological outcomes.[9]
- Interviews with family members of ICU patients revealed helpful roles that families take on in intensive care settings: "…active presence, patient protector, facilitator, historian, coach, and voluntary caregiver…" Researchers conclude that family members "…are an integral part of patient care in the ICU. They need to be recognized for the contributions they make and invited 'into the world and work' of ICUs." [10]

> *"She's not a visitor, she's my wife"… My husband wanted me there more than I was allowed. I feel it was a very cruel thing that was done to us."*
>
> — A Family's Story

- Family presence in adult critical care is not associated with increased infection rates.[11]
- Since implementation of family presence, the overall rate of infections decreased in a burn intensive care unit.[12]
- A randomized trial of 226 ICU patients in Italy showed that septic complications did not increase when visitor frequency and duration was chosen by the patient. Further, patients in the group with restricted visiting hours had a two-fold greater risk of major cardiovascular complications.[13]

Continued on next page

P resent yourself to the patient and to f
and friends who have been designated a
Explain that you will all be workin
as a team and that everyone's roles
are important.

A sk the patient, whenever possib
partner how they want to partic
decision-making. Discuss with t
support their participation.

R eassure care partners that their k
about the patient are valuable b
patient the best. Suggest what
patient's condition would be he
and when, where, and how to
will enhance the patient's quali

T rust that you and care partne
the best care and comfort fo

N urture your relationship
partners. On a regular bas
working **TOGETHER** as a

E ncourage the involvem
partners, especially whe
when transitions to oth
care settings are planne

R eview and agree upon
plans with the patie
preferences, values,

S upport care partne
roles as team men
Guide for Famili
Families with the

T alk about your role with your loved one. Introduce yourself to staff and describe your relationship to the patient and how you'd like to participate in care.

O bserve changes (physical, behavioral, emotional) in the patient and report them to health care providers. Ask staff what observations they would like you to routinely share.

G ather helpful information (current medications, medical history, other health care providers, and insurance) and bring it all to the hospital.

E nsure that you're present, if possible, at times when information will be shared and decisions need to be made. Keep your schedule for coming to the hospital manageable. Let staff members know how to reach you and be sure you know whom to contact for information when you're away from the bedside.

T ell staff if you have any concerns about the patient's condition or safety or if you are uncomfortable because "something just doesn't feel right."

H elp with decision-making about care and treatment. Be a second set of eyes and ears for the patient. Ask questions and take notes. Encourage your loved one to participate in decision-making to the extent he or she chooses.

E nlist help from staff members with whom you are comfortable so that they can support you and your loved one as you participate in care and decision-making.

R eady yourself for the transition to home or community care. Before you leave the hospital, make sure your questions and those of the patient have been answered. Know what will be needed afterwards (medications, treatment, equipment, follow-up appointments) and what changes in the patient's condition should be reported to health care providers.

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Taking action: Initial steps for change

1. Review organizational policy and website
2. Elicit input from patients and families
3. Review ***Better Together*** resources
4. Agree to one concrete step
5. Commit at leadership level

!

Questions & Discussion

Presence not “Visitation”

Participation not “Permission”

“Families are . . . respected as part of the care team – never visitors – in every area of the hospital . . . ”

Lucien Leape et al 2009

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