Aliens or Allies? Engaging Patients & Families in the Clinical Environment

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Objectives

1. Participants will learn skills for engaging Patients & Families into the clinical environment.

2. Participants will understand the principles of PFCC and how to express these principles in interactions with patients & families.

3. Participants will learn to recognize and act on opportunities to engage their patients & families.

4. Participants will be provided resources for continuing to improve their engagement skills.

5. Participants will understand the value of the patient & family as a resource in the clinical environment.
Our Story

Fear
Shame
Disrespect
Failure

But it is also a story of:

Partnership
Respect
Collaboration
Compassion
Empowerment
My mission

To share our experiences in partnership and true collaboration so that together we can improve healthcare for all of us.
Emotional Reactions of Patients & Families

- Fear
- Guilt
- Desperate
- Isolated
- Overwhelmed
- Anger
- Confused
- Denial
- Disappointed
- Helpless
- Panic
- Isolated
- Envy
- Loss
What Does Success Look Like?

- Calm
- Confidant
- Comfortable
The Call for Engagement

- HCAHPS: Patient Satisfaction Scores
- Partnership for Patients: PFE Network
- Joint Commission Standards: 24 hr access in hospitals
- Triple Aim for improvement
- Community based care
- Coordination of Care
- Transitions of Care
Engagement is not Entitlement
Setting the Table for Success

• Must have Top Down Buy In
• Managers must be on board
• Culture of Continuous Improvement
• Implied Importance
• PFCC is not new work, it is a new way to do the work we already do

• Family members are the most underutilized resource in the hospitalized environment
Institute for Patient & Family Centered Care

“Patient- and family-centered care is an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families. It redefines the relationships in health care.”

Respect & Dignity
Information Sharing
Participation
Collaboration
PFCC is Reciprocal

- Willingness to share
- Engagement level
Ingredients of Partnership

- Respect
- Choice
- Strength Based
- Individualization

- Flexibility
- Collaboration
- Empowerment
- Communication
- Compassion
Families are big, small, extended, nuclear, multigenerational, 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 for mutual support**… A family is culture unto itself, with different values and unique ways of realizing its dreams; together, our families become the source of our rich cultural heritage and spiritual diversity… Our families create neighborhoods, communities, states, and nations.

- Polly Arango, Family Voices, Algodones, NM
  AAP/Family Voices/MCHB/NACHRI and Shriners Hospitals for Children presentation
**Service Delivery Model vs Partnership Model**

**Service Delivery**
- Relies on service provider
- Recognizes the service provider as the expert
- Responsibility for the relationship lies with provider

**Partnership**
- All partners have equal weight
- All partners are recognized for their area of expertise
- All partners carry responsibility for the relationship
PFCC Concepts in Action

“When patients have an active role in their own health care, the quality of their care, and of their care experience, improves.”

“In the U.S., 78% of patients who said they were engaged in their care rated their care highly, compared with 43% who were not so engaged.”

David Emerald's TED* (*The Empowerment Dynamic) triangle provides an alternative to the Karpman Drama Triangle.

Creator

TED*

*The Empowerment Dynamic

Challenger

Passion-Based Outcome-Focused

Crisis

Dreaded Drama Triangle

(Karpman's Drama Triangle)

Persecutor

Coach

Rescuer

Victim

Anxiety-Based Problem-Focused
Impact on Patient-Provider Relationship

- Sets the table for collaboration
- Increases the communication
- Infuses the relationship with accountability
- Assures care plan will work within the family structure
- Empowered families more likely to share challenges
- Avoids Learned Helplessness
- Perception of care is improved
Benefits

• Decreases emotional distress with better coping during procedures, hospitalization, post-hospital period, and recovery**

• Provides more efficient and effective use of professional time and health care resources**

• Improves clinical decision-making on the basis of better information and collaborative processes**

**Family-centered care and the pediatrician’s role Guidelines, American Academy of Pediatrics, 2004 *
Cornerstones of Partnership

• Respect Functional Culture
• Identify strengths
• Family as a resource
• Keep an open minded
• Create opportunities for shared control
• Follow thru on what you say you will do
• Express respect for yourself, your staff and your patient & family
Honors cultural diversity and family traditions.

Recognizes the importance of community-based services.

Promotes an individual and developmental approach

Encourages family-to-family and peer support

Acknowledges the family as the constant in a patient’s life.

Builds on family strengths.

Supports the patient in learning about and participating in his/her care and decision-making
Benefits of Collaboration

Professionals develop greater depth of skills due to increased sensitivity to patients and improved, appropriate communication with families.

Providers are more at ease working with families so that the provider/family relationship is stronger with greater job satisfaction.

Family/professional collaboration at all levels insures a balance between perceived services system needs and the actual needs of families.

Families have greater feelings of competence in caring for their children with special needs.

Families’ dependence on the system decreases, as does cost.
Strategies for Partnering

• Open ended questions to clarify families’ understanding
• Provide choices
• Provide unbiased information
• Use interpreters
• Gather all appropriate resources before entering the room
• Assess knowledge of medical condition
• Use simple language
• Use many concrete examples
• Hear it, See it, Feel it, Do it!
• Patience
• The Teach Back Method

More Strategies for Partnering...

• Sit down, slow down as much as possible
• Eye contact
• Assess the patient and families understanding of the current medical condition
• Offer family comforts and resources
• TALK about your concerns
• Empower & guide the patient & families in their desire for information and knowledge
• Invite patients and families into the conversation
Staff Challenges in Clinical Environment

• Space Restraints
• HIPAA
• Limited time
• Sensitive Equipment
• Language Barriers
• Victims of Violence
• Maintaining the Status Quo
• Attitude Adjustment versus Education?
Some Solutions

Establishing the partnership early, helps providers and nurses to work collaboratively with the patient & family

Interpreters, language lines for medical information vs. conversation needs

Why is it there and what is it doing? Changes? Partnership opportunity regarding physical environment

Develop proficiency standards for all staff involved in family presence to ensure patient, family and staff safety

Written policies & procedures to support family presence; evidence-based clinical standards, (AACN, ENA, etc)

Nursing role for communication
Patient & Family Challenges

- Unfamiliar Environment
- Sensory overload
- Staff discomfort with emotional reactions
- Families’ lack of understanding
- Feeling in the way
- Guilt
- Fear of hurting the patient
- Restricted access
Roadblocks to Partnership

- HIPPA
- The Difficult Patient
  – Unrealistic Expectations
- Discomfort
- One more program
- Competing Priorities
- Disconnect between Executive Management and direct care staff
- Takes too much time
Supportive Guidelines

PFCC is a new way to do the same work

Interactions with 90% should not be based on interactions with 10%

Individualized Care results in a better perception of care

Partnership with patients & families makes your job easier!

Connecting with patients is the reason you went into healthcare!
The Potential…

Patients & Families working alongside Health Care providers, Physicians and Health Care organizations to design the new delivery of healthcare, ensuring that it works for patients, families, providers and our communities.
PFCC Partners is committed to building a community of healthcare providers, administrators, ancillary staff, patients and families coming together to define best practices, share resources, connect with peers and access support and tools for integrating PFCC into their organizations.

PFCC Partners recognizes that the quality of healthcare outcomes is improved when the expertise of the healthcare providers is partnered with the experience of the patients and families. From the **bedside to the boardroom**, patient & family centered care is about partnering to design policies, programs and individual care plans for the best possible outcomes.