Objectives

• Review historical perspectives of “Family” in the ICU.
• Examine the concept of “Family” presence in the ICU.
• Identify strategies to create “Family” engagement.
• Identify strategies to create “Family” empowerment.
KEY REFERENCES: Laying the Foundation for Family Engagement and Empowerment

- Cypress B. (Family Presence on Rounds) *Dimens Crit Care Nurs.* 2012;31:53-64.

KEY REFERENCES: Laying the Foundation for Family Engagement and Empowerment

How Involved are Families in Your ICU?

Not Present and Not Involved

Present and Actively Engaged in Daily Care
Patient and Family-Centered Care

• Patient-centered care definition:

“Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions.”

Institute of Medicine. Crossing the Quality Chasm. 2001.
Characteristics of Patient and Family-Centered Care

• Keep ICU patients and families:
  ➢ Informed
  ➢ Actively involved in decision-making
  ➢ Actively involved in self management

• Provide physical comfort /emotional support to patient and families.

• Maintain clear understanding of patients’ and families’ concepts of illness and cultural beliefs.

Institute of Medicine. Crossing the Quality Chasm. 2001.
Myths and Misconceptions

• Family presence interferes with care.
• Family presence exhausts the patient.
• Family presence is a burden to families.
• Family presence spreads infection.

Institute for Patient and Family Centered Care

http://www.ipfcc.org
Current Realities

• Social isolation separates patients from families.
• Families know the patient’s cognitive function.
• 90% of U.S. ICUs surveyed in 2008 had restrictive visitation policies:
  • 62% had ≥ 3 restrictions
  • Restrictions: hours, visitor #’s, visitor age

Ehlenbach W. JAMA. 2010;303:763-0.
Creating the Right Environment

- Family presence
- Family and patient engagement
- Family and patient empowerment
Family Presence: Flexible Visitation

• Concept of an open ICU.
• Daily meetings with the family.
• Healthcare providers learn to work while being observed by family members.
• Unit redesign efforts should consider impact of family presence:
  • Comfort
  • Sleeping

Let’s Open the Door

• *Today*: Resistance is from healthcare workers!

• *Why?* Fear of consequences and failure to understand the importance of families.

• *Family presence* at the beside is seen as a *privilege*, not as a necessary component of the patient’s care.

Evidence to Guide Practice Changes

- NO ↑ in infection rates.
- Restricted visiting hours ↓ CV complications.
- Actively involving families ↓ patient falls.

Adams S. Crit Care Nurs Q. 2011;34:3-10.
Fumagalli S. Circulation. 2006;113:946-52.
Practice Standard Expectation

- Unrestricted access for primary support person.
- This may or may not be the surrogate decision maker/legally authorized decision maker.
- Policies to prohibit discrimination related to the support person.
- Written practice document to limit visitors who infringe on the rights of others.

ICU Flexible Visitation: Patient Benefits

Decreases:
• anxiety, confusion, agitation
• CV complications
• ICU length of stay

Increases:
• feelings of security
• patient satisfaction
• quality and safety

Davidson J. Crit Care Med. 2007;35:605-22
ICU Flexible Visitation: Family Benefits

- ↑ family satisfaction.
- ↓ family anxiety.
- Promotes communication.
- Contributes to a better understanding of the patient.
- Allows more opportunities for teaching.
- ↑ family involvement in care.

Family Presence During Codes

• Family members offered the opportunity to be present during a code.
• 79% witnessed the code.
• Inviting family members to witness codes did not affect:
  • resuscitation characteristics
  • patient survival
  • emotional stress in the medical team
  • medico-legal claims

Family Presence During Codes (cont’d.)

• Sustained benefits.

• Short-term (90-day) and long-term (one-year) benefits - families that were offered the chance to witness codes were less likely to have:
  • PTSD symptoms
  • depressive episodes
  • complicated grief

Creating the Right Environment

• Family presence

• Family and patient engagement

• Family and patient empowerment
Inviting Families and Patients to Engage in Care

• Focus on activities that actively involve families in the patient’s care.
• Be sensitive - address questions and concerns.
• Facilitate communication - ↑ understanding of cultural/spiritual needs.
• Develop strategies for family engagement; provide education and role modeling.
Considerations for Family members

• **Concerns/fears:** Unique concerns and fears?

• **Skills/knowledge:** How can family be a part of the team?

• **System support:** What can the system do to promote patient and family engagement (PFE)?

How to Engage Family Members

Provide brochures → suggest ways that family members can help the patient:

• *Speak softly to patients and use simple words.*
• *Re-orient the patient (5 W’s + 1H).*
• *Talk about family and friends.*
• *Bring patient’s sensory aides (eyeglasses, hearing aids).*
• *Decorate the room with reminders of home.*
• *Participate in mobilizing the patient.*
• *Document the patient’s stay in an ICU diary.*
ICU Diaries

• ICU diaries decrease the incidence of PTSD after an ICU stay by >60%!

• Diary contents:
  • Calendar of events and/or milestones.
  • Photographs, both of the patient and the ICU.
  • Entries from staff and/or family.

• Utilize preprinted templates or websites
  • Great resource: http://www.icu-diary.org

Family Participation on ICU Rounds

• Who should participate?
  • Decision makers
  • Patients, whenever possible
• Invite them to join rounds.
• Provide an opportunity to ask questions, clarify.
• Ask them, “Do you have any additional concerns?”
• Participation fosters:
  • Bi-directional communication
  • Shared decision-making

Creating the Right Environment

• Family presence
• Family and patient engagement
• Family and patient empowerment
Empowering Family Members

• Family members = patients’ primary advocates.
• Provide them the tools and permission to speak up!
• Create a safe environment to speak openly.
• Create a culture where it is acceptable for our actions to be questioned.

• Three key areas:
  • Shared decision-making
  • Safety
  • Future care expectations
Shared Decision-Making

- Shared planning /decision-making:
  - Doing things *with* patients’ families, not *for* or *to* them
- Partnership = Patient + Family + ICU Team.
- Necessitates full disclosure of patient’s status.
- Necessitates regular meetings within 24-48 hours.
- Staff training needed in these areas:
  - Good communication skills
  - Meeting facilitation skills
  - Conflict management skills

Shared Decision Making: End-of-Life Decisions

- Physicians are hesitant to provide prognostic data because they think that surrogates are expecting certainty.
- Surrogates do not expect certainty, but they do value the conversation that includes prognostic disclosure in decision making.

Elements of Shared Decision Making: End-of-Life Decisions (cont’d.)

• Provide family brochure on bereavement.
• Use proactive communication strategies (i.e., longer conferences, > time for family members to talk).
• Involve Ethics consultations.
• Consider language barriers; include translators if necessary.

End-of-Life Family Conferences

- Look for opportunities to listen, respond to family.
- Acknowledge and address emotions.
- Pursue key principles of medical ethics and palliative care:
  - Exploration of patient preferences
  - Explanation of surrogate decision-making
  - Affirmation of non-abandonment

Safety

• Safety is *personal*!

  “*Patients and families can play a critical role in preventing medical errors and reducing harm.*”

• NPSF recommendations for patients:
  - Don’t go to the hospital alone.
  - Be sure you understand your plan of care.
  - Patients/families should be invited to participate on quality/safety committees.

National Patient Safety Foundation. 2014.
If You See Something Unsafe, Say Something!

• Give families permission to speak up.
• Teach them what should be happening.
• Ask them to hold the team accountable.
• Examples include:
  • Allergies
  • Hand washing
  • Untreated pain
  • Delirium symptoms
Future Care Needs

• Families have little appreciation for critical illness as a traumatic stressor.

• Provide education to adjust expectations:
  • Brochures on what to expect after ICU discharge.
  • Websites with patient/family-centered information.
  • Signs of depression, anxiety, and PTSD.

• Introduce post-intensive care syndrome (PICS).

• Create educational materials for discharge packets.

Brochure Example

• Handing patients and families written materials can be helpful in reinforcing education.

• Create documents at the appropriate reading level.

• Consider involving family members in the creation of materials.
Melissa and Doug’s Story: Recommendations for Others

http://www.icudelirium.org/testimonials.html
Online Resources

Families and Patients

- www.ardsusa.org
- www.ICUdelirium.org
- www.sepsisalliance.org
- www.myicucare.org/Adult-Support/Pages/Post-intensive-Care-Syndrome.aspx
- http://icusteps.org

Healthcare Professionals

- www.nice.org.uk/CG83
- http://www.icu-diary.org
- http://www.ipfcc.org
Questions?