Patient and Family Centered Care

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Objectives

• Learn through the patient’s eyes
  – Understand the experience from the patient’s view and NOT from our assumptions

• Be curious
  – Observe with curiosity and with respect for the staff that is providing care and service
What is patient and family centered care?

- 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.

- An approach that shapes policies, programs, facility design, and staff day-to-day interactions.
Patient and Family Centered Care

• Recognizes the vital role that families play in ensuring the health and well-being of family members of all ages.

• Acknowledges that emotional, social, and developmental support are integral components of health care.

• Promotes the health and well-being of individuals and families and restore dignity and control to them.
Patient and Family Centered Care

- Leads to better health outcomes and wiser allocation of resources along with greater patient and family satisfaction.
Core Concepts of Patient and Family Centered Care

- Respect and Dignity
- Information Sharing
- Participation
- Collaboration
Core Concept

- **Respect and dignity** - Health care teams listen to and honor patient and family perspectives and choices.
  - This is when you form the relationship, offering choices. Making them feel like they have control over their care. Providing emotional support and relieving anxiety.

- Patient and family knowledge, values, beliefs and cultural backgrounds are incorporated into the planning and delivery of care.
Core Concept

• **Information Sharing** - Health care practitioners communicate and share complete and unbiased information with patients and families in ways that are affirming and useful.
  – They can understand you in lay terms.

• Patients and families receive timely, complete, and accurate information in order to effectively participate in care and decision-making.
Core Concept

• Collaboration - Patients and families are included on an institution-wide basis.

  – Health care leaders collaborate with patients and families in:
    • policy and program development, implementation, and evaluation
    • health care facility design
    • professional education
    • in the delivery of care.
Core Concept

- **Participation** - Patients and families are encouraged and supported in participating in care and decision-making at the level they choose.
  - Where they are comfortable
  - This helps enhance independence and control
How can you apply these concepts into everyday practice?

• Establish a family and patient centered care committee or family advisory council
• Bedside report for nursing
• Family centered rounds
• Nursing hourly rounding
• Family as faculty
• Consider adding a parent patient to your clinician led activities for their perspective
Joint Commission Standard

• **Tell patients and their families that the single most important way they can help health care providers to prevent errors is to be active members of the health care team.**

• **Tell them how they can participate and encourage them to do so.**

Patients as Partners, Joint Commission Resources
Joint Commission Safety Goals

• Improve effectiveness of communication among caregivers.

• Encourage patients’ active involvement in their own care as a patient safety strategy.
  – Hand washing observation
PFCC and Safety

- Consider: medication errors
  - the most common medical error

- Patients and families are the first line of defense in monitoring medication administration and adverse reactions
  - During bedside report, review their medications
  - Review any new and continuing meds with common side effects
Common Medications Pediatric Emergency Department

Welcome to the Pediatric Emergency Department! It is important to us that you understand the purpose and possible side effects of the medicines you are taking while you are here with us.

Your nurse or pharmacist is happy to answer any questions you have during your stay.

- **Acetaminophen (Tylenol®)**
  - **Purpose**: Relieve pain or fever
  - **Possible Side Effects**: Side effects are rare but taking greater than 4,000 mg or 90mg/kg a day may cause liver damage

- **Acyclovir (Zovirax®)**
  - **Purpose**: Treat or prevent viral infection
  - **Possible Side Effects**: Diarrhea, upset stomach, vomiting, headache

- **Albuterol or Albuterol/Apratropium (Ventolin®/Duoneb®)**
  - **Purpose**: Help with breathing
  - **Possible Side Effects**: Fast heartbeat, headache, Shakiness

- **Amoxicillin/Amoxicillin-Clavulanate (Amox®/Augmentin®)**
  - **Purpose**: Treat or prevent infection
  - **Possible Side Effects**: Diarrhea, upset stomach, vomiting, rash

- **Ampicillin/Sulbactam (Unasyn®)**
  - **Purpose**: Treat or prevent infection
  - **Possible Side Effects**: Diarrhea, upset stomach, vomiting, rash

- **Azithromycin (Zithromax®)**
  - **Purpose**: Treat or prevent infection
  - **Possible Side Effects**: Diarrhea, upset stomach, abdominal pain

- **Cefazolin (Ancef®)**
  - **Purpose**: Treat or prevent infections
  - **Possible Side Effects**: Diarrhea, upset stomach, abdominal pain

- **Celecoxib (Celebrex®)**
  - **Purpose**: Treat and prevent acid reflux or bleeding in stomach or treat allergic reactions
  - **Possible Side Effects**: Diarrhea, upset stomach

- **Cephalaxin (Keflex®)**
  - **Purpose**: Treat or prevent infection
  - **Possible Side Effects**: Upset stomach, diarrhea

- **Ciprofloxacin (Cipro®)**
  - **Purpose**: Treat or prevent infections
  - **Possible Side Effects**: Upset stomach, diarrhea, headache, tendon injury (rare)

- **Clindamycin (Cleocin®)**
  - **Purpose**: Treat or prevent infection
  - **Possible Side Effects**: Diarrhea, upset stomach

- **Cyclobenzaprine (Amrix®)**
  - **Purpose**: Treat muscle spams
  - **Possible Side Effects**: Sleepiness, dizziness, dry mouth

- **Cyclopentolate (Cyclop®)**
  - **Purpose**: Dilate eyes for eye exam
  - **Possible Side Effects**: High heart rate, eye pain, blurry vision

- **Dexamethasone**
  - **Purpose**: Treat or prevent inflammation or prevent upset stomach
  - **Possible Side Effects**: High blood pressure, high blood sugar, trouble sleeping, mood change, stomach bleeding

- **Diphenhydramine (Benadryl®)**
  - **Purpose**: Relieve allergy symptoms, prevent trouble sleeping, or prevent upset stomach
  - **Possible Side Effects**: Sleepiness, dizziness, dry mouth, hyperactivity

- **Epinephrine**
  - **Purpose**: Treat allergic reaction, treat low blood pressure
  - **Possible Side Effects**: Anxiety, headache

- **Erythromycin (Hotylin®)**
  - **Purpose**: Treat or prevent eye infection
  - **Possible Side Effects**: Eye pain, eye redness, blurry vision

- **Famotidine (Pepcid®)**
  - **Purpose**: Treat and prevent acid reflux or bleeding in stomach or treat allergic reactions
  - **Possible Side Effects**: Diarrhea, upset stomach

- **Fentanyl (Duragesic®)**
  - **Purpose**: Treat pain
  - **Possible Side Effects**: Slow breathing, low blood pressure, sleepiness, constipation, upset stomach, itching

- **Hydrocortisone (Solu-Cortef®)**
  - **Purpose**: Treat or prevent inflammation, replace natural steroid levels, treat low blood pressure
  - **Possible Side Effects**: High blood sugar, trouble sleeping, mood change, increased appetite

- **Hydroxyzine (Atarax®, Vistaril®)**
  - **Purpose**: Treat anxiety or itching
  - **Possible Side Effects**: Dizziness, sleepiness, dry mouth

- **Ibuprofen (Adult®)**
  - **Purpose**: Relieve fever, bone or muscle pain, or inflammation
  - **Possible Side Effects**: Upset stomach, kidney injury, increased risk of bleeding and stomach ulcers

- **Insulin (Glargine/Aspart)**
  - **Purpose**: Treat or prevent high blood sugars or treat high potassium levels
  - **Possible Side Effects**: Upset stomach, kidney injury, increased risk of bleeding and stomach ulcers

- **Ketamine (Ketalar®)**
  - **Purpose**: Sedation, make the patient more comfortable
  - **Possible Side Effects**: Increased blood pressure or heart rate, confusion, slow breathing

- **Ketorolac (Toradol®)**
  - **Purpose**: Relieve bone, muscle pain, or inflammation
  - **Possible Side Effects**: Upset stomach, kidney injury, increased risk of bleeding and stomach ulcers

- **Lansoprazole (Prevacid®)**
  - **Purpose**: Treat or prevent acid reflux or bleeding in the stomach
  - **Possible Side Effects**: Diarrhea, upset stomach
Patient and Family Centered Care is a Journey
# Johns Hopkins Patient/Family Care Experience Transformation

<table>
<thead>
<tr>
<th></th>
<th>Past</th>
<th>Evolution</th>
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</thead>
<tbody>
<tr>
<td><strong>Culture</strong></td>
<td>Provider centered; intimidating</td>
<td>Care Team/patient partnership; open dialogue, more friendly</td>
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<tr>
<td><strong>Human Resources</strong></td>
<td>Individual excellence,</td>
<td>Accountable, engaged, empowered, exemplary multidisciplinary teams; culture of safety</td>
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<tr>
<td><strong>Systems</strong></td>
<td>Complex, data restrictive</td>
<td>Efficient, user-friendly, automated, continuous improvement, integrated information</td>
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<tr>
<td><strong>Facilities</strong></td>
<td>Antiquated, barriers to care</td>
<td>State-of-the-art, supportive</td>
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<tr>
<td><strong>Care Model</strong></td>
<td><em>Episodic, static, traditional</em></td>
<td><em>Integrated, continuous, evidence-based; innovation flourishes</em></td>
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At Johns Hopkins:
We promise to care for you, and about you, in a manner that places you and your family in the center of everything we do.
We recognize you as an individual with individual needs and expectations.
We recognize the importance of your family in your healing process.

Our commitment to patient-family centered care includes the exchange of relevant, timely and accurate communication; multi-disciplinary collaboration and teamwork; continuity throughout your transitions of care; coordination of care that meets your needs and preferences for health care, in a culture that values caring and service.
Examples of JHH Children’s Center Initiatives

- Expanded visiting hours to open visitation including “rooming in”
- Family presence in critical care situations
- Family participation in rounds
- Parent advisor on staff
- Sent team of interdisciplinary staff to IPFCC “Hospitals and Communities Moving Forward with Patient- and Family- Centered Care”
Initiatives Continued

• Family Advisors involved in presentations: Medical Student education, Resident Orientation, Nursing Education, Grand Rounds and JHH Inaugural Safety Summit
• Your Voice Matters Journal
• Family Meals and input into Guest menu options
• Gave input on new Children’s Center web design
• Worked with Parking office to offer discounted parking
• Bedside Report
Bedside Report

• Huddle
• 10 minute overview
• Safety briefing
• Then to individual rooms:
  – Introductions
  – What has occurred during the shift, what are we waiting for? - test results
  – Plan of care
  – Patient and family participate in discussion
  – Final safety check – fluids, pumps, drains, etc.
Benefits to Family Presence

- Patient and family witness staff communication
- Professionalism, organization
- Patients also feel a part of report and appreciate having input
- Opportunity to share information with patient and family
White Board

- White Board:
- Team
- Important information
  - Nutrition
  - Lab results
  - Last pain score
- Plan and goals
  - What service or provider are they waiting for?
Patient and Family Support

• Include families in your ongoing evaluation of processes

• What suggestions do patients/families have?

• Can use leader rounds, surveys, focus groups, or discharge calls to solicit information and feedback.
Josie’s Story

- 8-Year old female
- Dizziness, stomach ache
- Labored breathing
- Call to pediatrician
- Local ED
- Fluid around heart and lungs
- Transferred by ambulance to children’s hospital
Josie’s History

- 3-Month old: surgery for congenital cataracts
- Same hospital; trusted team and care
- Admitted to PICU
- Conditioned worsened, to CICU next morning
- Cardiac arrest, put on ECMO
- Diagnosis: viral cardiomyopathy
Josie’s Story (continued)

- Listed for heart transplant
- Berlin heart
- 396 days on wait list
- What to do?

Josie took walks with her Berlin Heart machine and an entourage of helpers.
The first smile from Josie in the CICU was a nurse's idea. Here's Josie squirting her brother with a syringe.

Mom and hospital teachers taught Josie to read. Nurses played with her daily. Friends came to visit. The girls convinced the nurses to build a fort with hospital sheets. We celebrated Christmas together among a family of nurses and doctors. Mother's Day was made special in the CICU. Father's Day was even better. The DE state Police fair came to the hospital and this kept Josie's spirit going.
Puzzles from Child Life kept us going on long days of waiting for a donor heart to come.

A therapy dog provided by the hospital's program lifted her spirits.

Music therapy was a highlight of the long days.
The **BEST DAY** was when Josie’s team allowed her to go outside and visit with her dog, Tara.
REALLY the best day... Josie was on the radio promoting her hospital the day her heart transplant and doctors saved her life.
Recovery and strengthening. Once we got in trouble for pedaling off the cardiac floor for more adventure and scenery.
Advocating
Whole Again and HOME
Dealing with Difficult Families

• **Listen actively**
  – When the other person is talking, stop and listen
  – Sometimes they just need to vent

• **Give some control**
  – Being admitted to the hospital is scary and frustrating
  – Attitudes and disagreements with the plan may not have anything to do with the plan

• **Ask questions**
  – What is at the foundation of their frustration?
    • Unclear about NPO status before a test
    • Why are they having a test

• **Involve the patient and family**
  – Encourage the patient or family to write down their questions, concerns, DR’s names etc.
  – Remember how many people they have already encountered
  – Medical terminology can be confusing

• **Stay professional**
  – Feeding in to a problem with poor attitude or unprofessional behavior is only going to make the problem worse
    • Put yourself in their situation
    • If you feel you are losing your temper, take some deep breaths, leave the room, know what is best and when to step away
Dealing with Difficult Families

• Establish rapport:
  – Acknowledge who is there
  – Explain what you are doing
  – Ask if there are any questions or concerns

• From this point on you keep the family in the loop

• Your goal is to deliver information to inform, empower, or soothe
Dealing with Difficult Families

• Set boundaries
  - Illness and stress on the family can bring out the worst in them
  - Be your patient's advocate, provide a calm and healing environment

• Know your limits
  - It is not your job to deal with entrenched family problems even if circumstances pull you into the drama
  - People have issues that are not going away just because a loved is sick
  - Offer a quiet place for a heart to heart with a social worker, chaplain, or yourself

• Safety first
  - Have protocols in place to deal with an escalating situations
    • Work with security
    • Post signage, give information
    • Consider visitation contracts
Family Presence in Critical Care

• Highly controversial topic! Earliest literature is from 1987.

• Opponents of FPDR are concerned with possible disruption of the code team, traumatic memories for patients’ families, and the risk of litigation.

• The evaluation of the psychological effects of family observation of resuscitation has so far come mostly from simple feedback, survey, or small observational studies.

• Critical Care Assoc., ENA and AAP, College of ER MDs, and AHA are supportive.

• Consumerism has become a driving force to demand as basic human right.
Family Presence in Critical Care

• Current evidence indicates that most families want to be present and would make the same choice again.
  – Fears that codes would be disrupted and families tormented by adverse psychological trauma have not been substantiated

• Many family members thought being present helped them to:
  – comprehend the seriousness of the patient’s condition and
  – know that everything possible had been done,
  – it eased their grieving.

• O’Connell et al. (2007) researched pediatric trauma activations and identified no significant difference in time to care:
  – log-rolling, radiographs, intravenous access, central line placement, intubation or chest tube insertion based on family members having been present in the trauma room

• These authors reported no interference of care by any family member in the 196 cases included in the study that had family members present.
In Summary

- Family Centered Care is important to be considered in decisions made moving forward with regard to care, renovation, policy development and education.

- You’re an important part in continuing this initiative

- Nelson Mandela Children’s Hospital- provides a great foundation to support this vision
References

• http://www.ipfcc.org/