UW Health’s Journey to Achieve a Patient & Family-Centered Culture

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Irene Ekleberry
Patient and Family Advisor
Meet
Irene Ekleberry

UW Health Patient & Family Advisor
The UW Health Enterprise
UW Hospital and Clinics & The American Family Children’s Hospital

- 566 Beds; 117 Outpatient Clinics
- 28,120 annual admissions
- 605,174 outpatient visits
- 47,379 ED visits
- 6 ICUs with 83 beds
- Level 4 NICU
- Level 1 Trauma Center
- NCI designated Cancer Center
- Organ Transplant Program
- Magnet Hospital
- Located in Madison, Wisconsin
• 1,356 physicians
• 2,633 staff
• Among the largest group practices
• 2,665,480 outpatient visits
• 411,052 unique patients
• Operates clinics in 30 locations

• 7 Joint Ventures:
  o Ambulatory Surgery Center
  o Dialysis Center
  o Reconstructive Surgery Center
  o Infertility Treatment Center
  o Sleep Center
  o Digestive Health Center
  o Wisconsin Institute for Psychiatric Care
Patient- and family-centered care is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.

Patient- and family-centered care applies to patients of all ages, and it may be practiced in any health care setting.
Patient- and family-centered care is working \textit{with} patients and families, rather than just doing \textit{to} or \textit{for} them."

\textit{IPFCC}

Mutually beneficial partnerships
Early Stages of Patient & Family-Centered Care

- 1990’s American Family Children’s Hospital launched 2 Patient/Family Advisory Councils.
- 2004 – first staff attend the Institute for PFCC.
- “Visitor” policy changed.
- 2006 1st Adult Patient & Family Advisory Council (PFAC) started.
- 2007 UHC PFCC Benchmarking Project reveals many opportunities
- Staff presented their work to PFAC and asked for input.
- Little feedback from staff about how PFAC’s input was used.
- PFAC members involved across organization, but passively.
- True partnership and engagement was lacking.
My Journey as a Patient & Family Advisor (PFA)

Helen Falck         Ship’s Captain     Irene Ekleberry
Helen’s Journey, 2000 - 2004

Helen Falck, 2006
• Patient and Family Advisory Council (PFAC) developed a mission statement, bylaws, and scheduled monthly meeting times.

• Began sending faculty and staff to the Institute for PFCC.

• Expanded PFAC to represent the partners of UW Health.
  o Added ambulatory to existing PFAC

• All Executives attended one or more PFAC meetings.

• Advisors appointed to:
  o Governance Quality & Safety Committee
  o Quality Council, Ethics, Executive Search committees & many others

• PFA’s began attending meetings, serving on work teams with faculty and staff.
• Held a PFCC planning retreat to identify priorities.
• Participated in the UHC Patient Experience Collaborative to improve staff responsiveness.
Must Dos:

1. Definition of PFCC & Philosophy of Care Statement
2. Introduce self when entering room - Patient/family understand role of each staff member entering room. (Encourage patient and family to ask questions of care team)
3. Education & Training (staff, MD's, PFA's, learners, UW Health-wide)

Other prioritized topics:

- Coordination of PFCC across UW Health
- Care Coordination
- Families Choice to be present with patient:
  - Clinic Visit
  - Treatment
  - Patient Procedure
  - Resuscitation
- Adult Interdisciplinary Model of Care
- Patient/family involved in rounds, beginning of care, and discharge planning
- After Visit Summaries/Bedside Report

Shift-to-shift report in front of patient and family.
“The most important part of her story in this moment is I do not tell her story for her. I listen. I am present and I am her support. Her healthcare story and decisions are hers to make alone.

Her co-morbidities make this last infection non-operable…

She is at peace and NOW she tells UW Health Physicians she is done. They partner with her and practice the best patient and family centered care I have seen. They listen. Everything changes.

Christmas was so important to my mother and her decision to end dialysis was timed so that she could have one last Christmas with our entire family.” – Irene Ekleberry
She is so at peace, she is happy...
SWOT Analysis in 2012

**Strengths**

- CEO & other leaders commitment to PFCC
- 80 people had attended the Institute for PFCC
- High levels of advisor engagement
- Agreement to hire a PFCC Program Manager
- Additional PFACs starting
- Interdisciplinary Model of Care Rounding
- PFCC training developed

**Weaknesses**

- Diffuse responsibility, redundant efforts
- Lack of infrastructure, budget
- Misconceptions of PFCC
- Faculty engagement
- Efforts have been grass roots
SWOT Analysis (cont.)

Opportunities

• Develop infrastructure, hire PFCC Program Manager
• Teach in School of Medicine
• Create Office of Patient Experience
• Develop PFAC Coordinating Committee (rep from each PFAC)
• Buy-in and engagement to speed culture change.
• Additional recruitment of PFAs

Threats

• May not get needed attention as one of many organizational priorities
• Lack of a designated physician champion for PFCC
• Insufficient resources
• Lack of understanding what PFCC is and is not
• Lack of patient engagement associated with suboptimal outcomes
Current State: A True Partnership

- 11 Advisory Councils – Primary Care, UW Health Adult, My Chart, AFCH, Primary Care Peds, Transplant, HIV Clinic, Yahara Clinic, Oncology, Breast Center, Northeast Clinic.

- 150 Advisors and growing

- Developed PFAC Coordinating Committee to provide coordination across PFACs and common on-boarding

- Many PFAs now working on task forces, not necessarily needing to be on PFACs.
Current State (cont.)

• PFCC Program Manager hired.
• Updating facilities; welcoming, supportive healing environments
• Family-centered Interdisciplinary Model of Care Rounds
• Process in place to request PFAs to partner with us in workgroups and committees.
• Inpatient dyads responsible for improving the patient/family experience
• Mandatory Introduction to PFCC Training for all hospital staff
• PFCC principles and behavioral expectations are embedded into UW Health Performance Standards.
  o Annual performance reviews provide an opportunity to coach on desired behaviors.
• Checklist for partnering with patients and families
• Research panels – inviting PFAs
• Annual Patient/Family Advisor Recognition Dinner
• Emergency Department supports family participation during any part of the patient’s ED evaluation, including all procedures and resuscitations.
• Inpatient Medical Director of Patient Experience
Performance Improvement

• Patients/Families involved in most large scale improvement efforts, for example:
  - In all phases of development of a new healthcare campus (multi-year project)
  - Discharge Collaborative Steering Committee
  - Primary Care Redesign
  - Advanced Care Planning Steering Committee
  - Interdisciplinary Model of Care Committee
PATIENT AND FAMILY ADVISOR
PARTNERSHIP PROGRAM

We Need You!
Are you a UW Health patient or patient family member? If so, we want to partner with you to create the best patient experience possible at UW Health. The only way we can do that is with your unique perspective and expertise as a Patient and Family Advisor.

What is a Patient and Family Advisor (PFA)?
As a volunteer Patient and Family Advisor, your voice on the UW Health team offers a perspective only a patient or family member can provide.

Why Be an Advisor?
- Share perspectives and experiences to improve patient care
- Help design/redesign facilities or processes for efficiency and ease
- Help write and design patient education materials
- Serve on hiring committees for UW Health leadership positions
- Participate in ongoing patient and family advisory councils
- Learn valuable skills like how to provide feedback and be an effective team member
- Know you are making a difference

UW Health
uwhealth.org/PFAPartnerships
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<tr>
<th>PFA Level</th>
<th>Who Does it Include?</th>
<th>Requirements</th>
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<tr>
<td>Level 1</td>
<td>1. One way communication only&lt;br&gt;2. Focus Groups (No Exchange of Proprietary information)&lt;br&gt;3. Informal feedback from patients</td>
<td>✓ Centralized Tracking Encouraged</td>
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<td>Level 2</td>
<td>1. Two-way communication/partnership&lt;br&gt;2. General PFAs&lt;br&gt;3. PFAC Members)&lt;br&gt;4. Focus groups or projects where proprietary information is exchanged</td>
<td>✓ PFA Orientation&lt;br&gt;✓ Confidentiality Agreement&lt;br&gt;✓ Centralized Tracking&lt;br&gt;✓ Background Check</td>
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<td>Level 3</td>
<td>1. Formal volunteer&lt;br&gt;2. Adult PFAC members&lt;br&gt;3. PFAs working in patient care areas or with patient contact</td>
<td>✓ PFA Orientation&lt;br&gt;✓ Confidentiality Agreement&lt;br&gt;✓ Centralized Tracking&lt;br&gt;✓ Health Assessment&lt;br&gt;✓ Background Check</td>
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Recent PFA Contributions

• Intentional Rounding Implementation Plan
• Endorsement of new policy for pets in the hospital
• Advanced Care Planning Steering Committee
• HIV/AIDS Comprehensive Care Program

• Discharge Collaborative Steering Committee & Rounding
• National presentations
  o IPFCC, ACHE, UHC, etc.
• TLC (ICU) Retreat
• First Day Surgery Visiting Guidelines
• Patient Education Events
Intranet & Web Presence
Hearing from our PFAs

Patient and Family Advisor Partnership Program

UW Health
Future State

• Strategic Plan identifies Patient & Family Experience as a priority; to optimize the experience and restate our commitment to being an organization that is centered on respectful care of the patient and family and responsive to their values, perspectives and needs.

• Hiring a Chief Experience Officer.

• Consistent Service Standards across UW Health.

• Implement additional strategies in response to recent Self-Assessment. [http://www.aha.org/content/00-10/assessment.pdf](http://www.aha.org/content/00-10/assessment.pdf)
Greatest Organizational Challenges

• Recruitment of PFAs for 1st Advisory Council.
• Recognizing that PFCC ≠ doing whatever patients/families want.
• Staff enthusiasm led to disjointed efforts and slowed the pace of change.
• Deciding if all PFAs should be volunteers.
• Staff readiness/awareness for PFCC and PFA involvement.
• Becoming a learning organization (hearing the good, the bad and the ugly).
• Managing the number of processes that need improvement once you see the issues through PFCC-colored glasses!
What can we do better?

- What can we do better? A LOT!
  - Sharing Patient Stories
  - Improved electronic communication with PFAs.
  - We have made great progress, but have not “achieved” a culture of PFCC in all quarters.
    - Some resistance to redesigning care processes around the patient and family.
    - HCAHPS scores
    - Expand number of services that welcome family presence throughout all aspects of the episode of care
Good-bye, Mom

“Now we go to hospice. Good-bye mom. I will continue the journey without you, but not without you.

We are continuing the journey, and you are never far from my heart. I am (still) a Patient and Family Advisor. I am partnering with UW Health to enhance the patient and family experience, and I love every minute of it.

It is our legacy…”

Mom hanging on at hospice, 2009
I know my journey as a Patient & Family Advisor is an important one.

2011: Helen Falck’s family
Rita Nash, Irene Ekleberry, Gene Falk, Blair Ekleberry
Irene’s Summary Comments

• It has been an amazing journey – input affects change, and sometimes immediately.

• Important to be able to contribute to change after my mother’s experience at UW Health.

• Patients and families are fully engaged from the bedside to the Board Room.

• There is always genuine desire on the part of the organization and staff; always inclusive, transparent. I see the whole story.
Lessons Learned
(written by our PFAs)

• Trickle Up-Trickle Down are both necessary;
• Tenacity and Patience are Key;
• Healthy Debate is Desired;
• Nothing About Me without Me;
• Secure e-Communication is Challenging;
• Stories are Priceless!
The woods are lovely, dark and deep,
But we have promises to keep,
And miles to go before we sleep,
And miles to go before we sleep.

Robert Frost
Stopping by Woods on a Snowy Evening

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