From Dissatisfaction To Collaboration: 
The Spectrum Of Patient Engagement

Brenda Radford, Director, Guest Services, Duke University Hospital
Tiffany Christensen, Patient Advocate, Duke Health System
Objectives

- Identify key areas in which engaging patients effectively can increase satisfaction and de-escalate difficult situations.
- Demonstrate concrete strategies for leadership and staff to have difficult conversations resulting in mutually beneficial resolutions.
- Integrate the patient and family voice as an essential part of feedback and performance improvement using your PFACs.
We strive to make the patient experience the best it can be and...

At the end of the day...patients are sick, tired and even in the best of care, they face a difficult reality.

Not everyone is able to cope.
Identity Thief – Patient or Prisoner?

Have their clothes taken away
Are assigned a number; known by that number
Turn over their valuables
Lead lives according to the institution’s schedule
Enter a bleak environment (compared to home)
Have very few choices and little control
Little privacy
Must eat food that may be distasteful to them
Difficult person or a difficult behavior?

- The many stresses of illness effect everyone differently
- Sometimes, a personality trait is amplified
- Sometimes, the person becomes unrecognizable
- No matter what, the behavior is not who they are it is a manifestation of their ability to cope
- Try to resist labels and just address the behavior as it is today
- Forgive the person and assume this is not “all of them”
- When handing off, use facts not negative descriptions
How We Communicate?

Face to Face Communication
- 55% Body Language.
- 38% Tone of Voice.
- 7% Words Used.

Telephone Communication
- 82% Tone of Voice.
- 18% Words Used.
Hostility Curve:
Know when to engage and when to back off

Service Recovery Model
(the pause is a gift)

SLOWS DOWN

Takes off

Cools off

RATIONAL
(YOU)

PROBLEM SOLVED
Avoid “Words that Don’t Work”

• What does that mean to you?
How do we avoid taking difficult interactions personally?

How do we prevent a difficult interaction from effecting our next interaction?
Communicating with challenging people and the patient experience

The sum of all interactions, shaped by an organization’s culture, that influence patient perceptions across the continuum of care.

The Beryl Institute
Communication Model

relate™

- explain
- answer
- express appreciation
- reassure
- listen
- take action
Communication Strategies in the midst of conflict

• *Practice Active Listening*: Same story, different details

• *Ask Questions*: Make sure you’re clear, don’t assume

• *Acknowledge Perspectives*: There isn’t always a right and wrong, sometimes it is 2 rights and sometimes it is 2 wrongs

• *Use neutral language*: Avoid projection; “you are in an awful situation”
Communication Strategies that keep you grounded

- **Know Yourself and your Style**: Confidence in these interactions is key. Be you, know what works for you, and you can brave a storm—share your style.

- **Use “I” or “we” language**: We don’t know how the patient/family/staff will feel or respond. All we know is what we know.

- **Stick to facts**: “The patient states,” “What I observe,” “Dr. Baker stated”

- **Be Honest**: Pacifying or leaving out key pieces of information will come back to bite, state the truth even if you have to ask for time to prepare.
It’s your turn!
The patient who knows his body

Joe was admitted through the ER for a rash which was believed to be an allergic reaction to chemotherapy. In addition to cancer, the patient has bipolar disorder. The patient is upset because he feels that his rash is not being taken seriously. Although the rash has resolved, the patient insists he knows his body and needs further evaluation/treatment. The patient states that, if he were to go home now, he would likely go into anaphylactic shock and be at risk of dying at home or coming right back to the ED.

How would you apply the RELATE model in this situation?
The patient with unrealistic expectations

Sue, admitted after a minor surgical procedure with expected discharge the following day. Patient and fiancé continually state that pain is not under control and have contacted PVR and have called a Condition H. Seven days following admission, patient agrees she is ready to be discharged on Saturday. At time of expected discharge the patient complains of new pain. Fiancé and patient insist that patient have CT, x-ray, etc. to diagnose new condition. Despite physician teams explaining that these procedures would not provide the type of information they seek, patient refuses discharge until imaging studies are done.

How would you handle this patient situation, Using communication strategies in the midst of conflict?
The patient who manipulates

- Today is your first day on rotation. Jennifer has been on the unit for 3 weeks for a sickle cell flare and you are seeing her for the first time. Nursing staff and residents report that Jennifer appears very comfortable but is stating her pain is a 10 out of 10.

- When you go in to visit Jennifer you find her on the phone, reclining and laughing while eating french fries. Jennifer gets off of the phone and you explain that the plan for today is to begin weaning from IV pain medication to oral. Jennifer suddenly becomes angry and states that she is not ready to go to oral narcotics. Patient demands to speak with a patient advocate and get a new doctor/in-patient team.

How do you apply these steps to this situation using communication strategies to keep you grounded?
Defining Patient Grievance

A Patient Grievance is a written or verbal complaint by a patient, or the patient’s representative, regarding the patient’s care (when the complaint has not been resolved at that time by staff present), abuse or neglect, or the hospital’s compliance with the CMS Hospital Conditions of Participation (CoP).
Complaint Process

• Complaints
  – Issues that are handled “on the spot”
  – Billing issues (with no care issues)
  – All lost and found issues

Follow-up on complaints:
  – May be by phone, in person or by letter
  – Letter is not required
Grievance Process

• **Grievances**
  – Issues not handled “on the spot”
  – Any letter, e-mail, fax that comes after the patient has left
  – Any attachment or letter with a patient survey
  – Any request by patient or patient representative to file a formal complaint/grievance
  – Any verbal or written complaint regarding abuse, neglect, patient harm or hospital compliance with CMS requirements
  – Medicare beneficiary billing complaints
  – Billing issues if the patient or their representative states they will not pay because of care or treatment issues

• **Follow-up on Grievances:**
  – CMS feels that the majority of an organization’s grievances should be resolved and responded to, in writing within 7 days
  – Follow-up is required in writing in accordance with CMS standards and guidelines, and your organization’s grievance policy
CMS Grievance Exceptions

• Not required to provide information that can be used against the hospital. These are designated as Risk Management "WATCH" files.

• Anonymous surveys – but required to investigate and internally address issues.

• Anonymous calls - but required to investigate and internally address issues.
CMS Complaint Follow-Up

Complaint follow-up may be

- By phone,
- In person, or
- By letter, although a letter is not required
Grievance Follow-up

Grievances require a timely resolution with a written response of the outcome of the grievance review and investigation and include:

- The name of the hospital contact person
- The steps taken on behalf of the patient to investigate the grievance
- The results of the grievance process
- The date of completion
Responding to the Patient

- Resolution is requested to be sent in writing within 7 (calendar) days.
- CMS will review to be sure that a response is sent on an average of 7 (calendar) days.
- If cannot resolve within 7 (calendar) days, send an acknowledgement letter with date when resolution/response letter will be sent (in accordance to hospital grievance policy).
Responding to the Patient

• Resolution is to be communicated appropriately, in a language and manner the patient or patient’s legal representative understands

• The hospital may use additional tools to resolve a grievance- i.e. meetings with the family, or telephone conversations

• In all cases a written notice must be provided

• If a patient communicates to the hospital via e-mail or requests a resolution by e-mail, an e-mail response is acceptable
No Matter how difficult, there is only one thing we have control over…ourselves

Addressing difficult behavior in a healthy way is a CHOICE and takes practice. Support each other in doing this.

ALWAYS:

Be professional
Be respectful
Be honest
Be prepared
And sometimes, no matter what, people will be dissatisfied…
Part II
PFE to improve the patient experience
Diagnosed at 6 months old with the gift of cystic fibrosis
By the age of 22, I was in need of a double lung transplant to survive. I waited 4 years for my “call”
Facing Medical Error

Surgical Error:
“Wet Run” and an apology

Ripple Effect of Reactions:
In the OR
In the Transplant Protocols
In Safety Procedures Hospital Wide
I waited 1 more year for my first set of donor lungs.

Now, due largely to the surgical error, I was 87 pounds and my lung function was 18% of capacity.
In June of 2002, my lung function started to drop.

I was diagnosed with my second terminal illness 6 months later. I had Chronic Rejection.
I asked my doctors if I could have a second lung transplant.

They said no.
After the stages of grief…
the soft arms of acceptance
We got a new transplant coordinator.
Patients are so different! Diversity of:

- Experience with healthcare
- Cultural/family/regional background carrying conscious or unconscious beliefs
- Motivation based on illness, prognosis etc
- Support varying from invasive to non-existent
- Socio-economic background shifting focus or worry from health to something else (including health literacy)
- Personality!
PFCC Best Practice: High Impact Story-Telling

Do you think this might open the door to considering PFCC important?

So you have their attention….now what?

How do we operationalize PFE?
Person- and Family-Centered Care is putting the patient and the family at the heart of every decision and empowering them to be genuine partners in their care.

~Institute for Healthcare Improvement
We can not improve the patient experience unless we have patients and families sitting with us at the table of change!
Patient and Family Centered Care Guiding Principle:

Collaboration
What is a PFAC?

A Patient and Family Advisory Council (PFAC) partners patients and families with members of the healthcare team to provide guidance on how to improve the patient and family experience.

Through their unique perspectives, they give input on issues that impact care, ensuring that the next patient or family member’s journey is easier.

~Meghan West and Laurie Brown, BJC Healthcare
How do we primarily receive patient/family feedback?

How is the feedback we get from PFAs different?
Early Model for PFACs

• In 1997, Dana-Farber Cancer Institute's inpatient beds were moved to Brigham and Women's Hospital. Patients and family members, concerned about the changes, wanted to work with staff to protect quality of care and ensure patients' needs were the highest priority. The result was the creation of the Adult Patient and Family Council. Key hospital leaders and staff committed their institutions to patient- and family-centered care through the formation of the Council.
7 Steps to Sustainability

1. Step 1: PFCC and PFACs
   - Raising awareness of the “why”

2. Step 2: Preparing
   - Leadership buy in and planning

3. Step 3: Structure
   - Key decisions about PFAC approach and logistics

4. Step 4: Recruiting
   - Clear goals for PFA selection including Diversity First

5. Step 5: Training
   - Comprehensive for PFAs and staff

6. Step 6: Launching and running
   - Gathering of agenda items and good facilitation

7. Step 7: Sustaining
   - In it for the long haul!
The role of leadership

Without engaged health system leadership, this becomes a grass-roots effort and cannot make the desired impact.

Duke’s transformational “retreat” with leadership changed the way PFACs functioned from that day on.
Choosing Associate Co-chairs

A staff co-chair should:

Be a “person of influence” within the area/organization

Have time available to devote to the project

So that he/she may…

Work to obtain organizational support for the council

Help to define the council's role in the organization
7 Steps to Sustainability

Step 2: Preparing

- Leadership buy in and planning
Step 2: Planning for Launch

- Share the vision with leadership (as often and with as many people as necessary) before implementation
- Ask 1: Bring ideas, challenges and new plans to the council as far upstream as possible
- Ask 2: Visit from time to time to offer thanks, guidance and motivation
When sharing the vision, be mindful of PFAC PTSD
7 Steps to Sustainability

Step 3: Structure

• Key decisions about PFAC approach and logistics
With leadership, make key decisions about structure such as: Start with PFAs or PFACs?

PFAs going out to existing committees
- Faster launch
- More risk
- Frontline Engagement

PFACs with staff coming to PFAs
- Slower launch
- Less risk
- High level engagement
Standard Structure for PFACs
(otherwise they may not be PFACs)

Patients and family members (80%)

Staff (20%)

Visitors
2 volunteer tracks for PFAs

Extended application process required for PFAs desiring to work on PFAC projects involving direct patient/family contact.

Simple application process for PFAs desiring to work only on PFAC projects within meeting rooms or non-patient events/projects.

Recruitment
Prior to Recruitment: Organize your launch

- Gather Exec team and all other employees planning to regularly participate in PFAC
- Set meeting frequency, food, day of the month (1st Monday, 3rd Thursday) time and location
  - This can change after launch but there needs to be a framework for those applying
- Set goals for membership
- Recruitment plan and launch date
- Brainstorm topics
- Explore questions and concerns
7 Steps to Sustainability

Step 4: Recruiting

- Clear goals for PFA selection including Diversity First
Recruitment
Where do I find my PFAC people?

- Physicians, colleagues
  - Advisor recruitment email template
- Peer support groups
- Volunteer services
- Patient satisfaction surveys, Patient Relations Dept.
- Newsletters
- Websites
Choosing Effective PFAs

An effective advisor:

- Has personal patient experience or has acted as a caregiver (usually but not always)
- Has processed through grief or loss
- Can generalize personal experience to provide feedback on overall patient experience
- Has time to commit to regular meeting attendance as well as outside volunteer opportunities
Choosing Effective PFAs

An effective advisor:

- Possesses soft skills necessary for working in a collaborative environment:
  - Active listening
  - Clear, tactful verbal communication
  - Willingness to speak in front of group/leadership
- Shows concern for more than one issue
Choosing effective PFAs: Diversity First

• Recruitment:
  – Think about diversity of perspective, cultural traditions in addition to personal qualities
  – Remove barriers from volunteer process
  – Add language to recruitment materials

• PFAC composition
  – Advisors should represent the population served
  – Give under-represented populations a voice
1. Panel members use PFAC application as a guide
   • Assess ability to articulate history, interest, strengths

2. Describe PFAC structure, activities and goals

3. Outline PFAC time-commitment needed and discuss any obstacles/concerns

4. Answer questions, explain next steps and invite to witness a PAFC meeting
7 Steps to Sustainability

Step 5: Training

- Comprehensive for PFAs and staff
Training paves the road for success by identifying and working through potential barriers at the start.
Why the PFAC Training?

3 hour training allows brand new members to start participating more effectively and confidently much sooner…

“I wish we had this training when I started. It has taken me so long to feel like I understand what is going on. This would have really helped.”
What is included in the PFAC training?

- PFCC and PFACs
- Overview of organization
- History of organization’s PFAC program
- Putting the PFAC to Work—success stories and lessons learned
- Building Your PFAC: the PFAC structure from naming the PFAC to choosing a focus
- How to effectively recruit and choose patient/family advisors
- Diversity First
- Sustaining a Council with varying opportunities for engagement
- Tools for measuring impact and PFA/Staff satisfaction
- Setting advisors and staff up for success: communication, the buddy system and working through PFAC PTSD
Key portion of training: What is my role?

PFAs

Feedback
projects, initiatives, experiences, philosophies

Staff Advisors

Guidance
topics/ approaches that have impact
Effective Advisor Communication

- Make observations: "I noticed trash on the area by the stairs on the 3rd floor"
- Make requests: "Would it be possible to...?"
- Engage in open dialogue: "Have you tried...?"
- Show empathy: "I’m sure you’ve thought about this but..."

- Make evaluations: "Your hospital is dirty"
- Argue for change: "You should..."
- Make demands
- Make judgments: "Doctors don’t care"
- Wear the expert hat
- Become impatient with lack of change
7 Steps to Sustainability

Step 6: Launching and running

- Gathering of agenda items and good facilitation
Step 5: Launching
What do PFACs talk about?

Simple PFAC Topic Examples
- ABMT falls communication for RNS and signs
- New patient brochure language
- Signage for ED entrance

Sophisticated PFAC Topic Examples
- Ebola communication for ED patients and community
- Timing of release of test results via EMR
- PFCC model

Examples of Special Projects
- ACP Videos
- TeamSTEPPS for Patients
- “Secret Shopper”
Focus Group Examples

Building/room design
- DMP and Duke Cancer Center: Visitor recliners
- Furniture selection

Programs
- “Condition H”
- Ethics and futile care

Communication
- Billing letter template
- Holiday resource brochure for patients & families
PFA Engagement

- PFAC
- Table
- Staff/Org Meeting
- Speakers’ Bureau
- PFP

Launching and Running
PFA Engagement: Highlight on PFP

- Peer rounding
- “Secret Shopper” aka Quality Observer utilizing focus tool
  - Passive (waiting room)
  - Partnering with a patient “Real Time”
  - Recording personal patient experience
  - Presenting as a patient or visitor (HUC example)
- “Walk About” with focus tool
PFA Engagement: Highlight on PFP (cont.)

• PFP as peer navigator
  – Non-clinical assistance with way-finding, support resources, patient perspective on helpful coping strategies etc.

• PFP involved in interviewing new staff/providers

• Representation on hospital board and other high level leadership meetings in which the patient experience may be impacted
PFAC or PVR?
*The delicate balance*

A one-time concern

Pattern of concern that the PFAC can address

Launching and Running
7 Steps to Sustainability

Step 7: Sustaining

• In it for the long haul!
Division of Labor
<table>
<thead>
<tr>
<th><strong>STAFF</strong></th>
<th><strong>VOLUNTEER</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Program Coordinator</strong></td>
<td><strong>New Applicant Greeter</strong></td>
</tr>
<tr>
<td>- Send PFAC application to interested applicants</td>
<td>- Initiate contact with potential PAC applicants</td>
</tr>
<tr>
<td>- Collect and file completed applications</td>
<td>- Uses guide to explain PFAC Program and process for becoming an advisor</td>
</tr>
<tr>
<td>- Request background checks</td>
<td>- Forwards names of interested applicants to Exec Team for interview</td>
</tr>
<tr>
<td>- Maintain volunteer files for all volunteer patient/family advisors</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Interview Scheduler</strong></th>
<th><strong>Meeting Minutes Master</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Schedule 30-minute interviews for new PFAC advisor applicants with:</td>
<td>- Record PFAC meeting minutes using Meeting Minutes Template</td>
</tr>
<tr>
<td>- At least one member of PFAC executive team</td>
<td>- Send meeting minutes to PC and Meeting Organizer</td>
</tr>
<tr>
<td>- One staff advisor</td>
<td></td>
</tr>
<tr>
<td>- Pt/Family Co-chair or other trusted advisor</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Meeting Organizer</strong></th>
<th><strong>Meeting Communicator</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Secure &amp; confirm speakers/presenters for PFAC meeting</td>
<td>- Solicit PFAC Executive Team members for topics/presenters for upcoming PFAC meeting</td>
</tr>
<tr>
<td>- Complete agenda template</td>
<td>- Forward topics and presenters suggested to Meeting Organizer</td>
</tr>
<tr>
<td>- Send completed agenda to Meeting Communicator for distribution 1 week prior to PFAC meeting</td>
<td>- Send completed PFAC meeting agenda (once received from Meeting Organizer) &amp; meeting minutes to all PAC members</td>
</tr>
<tr>
<td>- Print agenda and meeting minutes</td>
<td></td>
</tr>
<tr>
<td>- Store agendas and MM in agreed upon location for reference later</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Tracker</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>- Update Issue Tracker following each PFAC meeting</td>
</tr>
<tr>
<td>- Share current version of Issue Tracker during PFAC meetings</td>
</tr>
</tbody>
</table>

**Sustainability**
Issue Tracker

- Quantify impact of PFAC feedback
  - Benchmarking
    - Baseline measures
    - Goal setting
  - Collect updated measures in 3, 6, 9, 12 mos.
Consider including:

- Number of councils in operation
- Number of advisor volunteers & total hours of volunteer service
- Number of projects, initiatives, and special events to which advisors have contributed
- Evaluation scores: advisors & presenters

http://www.ipfccc.org/advance/topics/annual-reports.html
Reporting Structure

Organizational Leadership, Board Members
- Annual Report

Departmental Leadership
- Annual Report
- Meeting Minutes

PFAC Exec. Team, Council Members
- Meeting minutes
Impact Measurement:
PFAC Presenter Evaluations
Process Improvement: Advisor Satisfaction Evaluations
Your PFAC Plan

Key concepts to remember

• Take-away list

Top 3 “to-do’s” when you get back

• Action items
Questions?

Thank you!
Exhibitor Reception

5:00-6:30 PM

*Dallas & Trinity Foyers*