



*Partnering with healthcare leaders  
to forge quality & safety outcomes.*

---

# Making Sense of the Patient Experience: Partnering with Patients and Families

Barbara Balik, RN, EdD

June 20, 2011

# Doing To

---

“I talk – you listen – you do”

“We fix it for you”

- Characterized by terms such as:
  - “Compliance or noncompliance”
  - Families are visitors subject to visiting hours determined by us
- Hospitals as elegant prisons where we determine everything
- Organizational and professional control
- No openness or transparency; where even lies (communication with the intent to deceive) are tolerated to protect providers or the organization; e.g. withholding information about harm to you

# Doing To

---

- Waste filled with no recognition of waste
  - E.g. Ventilator associated pneumonia is a 'known complication of care' and thus accepted; not see as a source of waste
  - Waste of staff time with unworkable systems
- Examples
  - Fathers/partners excluded from births
  - Medication bottles lacking drug name on labels because physicians thought it would upset or confuse
  - Withholding diagnosis of cancer – fear that the patient would lose hope
  - Children did not feel pain as much as adults thus needed less pain medication

# Doing To

---

We know we are *doing to* when:

- We set visiting hours
- We control all schedules
- We determine what and when you eat
- Information is not shared in patient presence or if it is, it is not understandable; no health literacy
- There is helplessness – when the patient/family say:
  - I don't know what happens next
  - I don't know who is in charge of my care
  - I don't feel like you know me

# Doing For

---

“We plan – We do – then ask ‘was it OK?’ ”

“We help you”

- Characterized by:
  - Benevolence – wanting to be kind
  - Awareness of a patient/family perspective
  - Use of terms: Patient Satisfaction or Service Excellence
    - Some actions seen as chasing the numbers or going through the motions
  - Experience is separate from quality & safety of care
- Institution or site focus to improvement not the total patient experience or journey
- Professional or organizational control remains
- Family presence rather than family-as-visitors emerging
- Emerging transparency when harm occurs yet legal objections remain; emerging voluntary public reporting of data yet not all data reported

# Doing For

---

- Waste filled yet some waste now recognized
- Some sources of waste not seen:
  - The waste of patient/family knowledge in designing effective means to improve their health & healing
  - The waste of patient/family knowledge to improve programs and services
    - E.g. coffee & muffins vs. 'who is the physician in charge of my child's care?'
    - Square footage for waiting rooms and waits
- Care providers may feel disconnected
  - "Does this mean I can't challenge a parent who does not want to immunized their child?"; does this mean if a woman wants a elective induction of labor before 39 weeks I have to do it?"
- In attempts at partnerships, we may ask patients to do our work
  - E.g. remind providers to wash their hands



Partnering with healthcare leaders  
to forge quality & safety outcomes.

# Doing For

---

You know you are *doing for* when:

- Family presence is defined by the patient
  - You keep the patient in mind when designing or improving programs
  - Patients are asked to react to program or facility design after the design is complete
  - Healthcare staff think they can represent a patient perspective since they have been a patient
  - There are dedicated efforts to improve the patient experience often separate from quality & safety of care
  - We *manage your expectations* about waiting
    - The intent is to get you to tolerate our poor systems by explaining them
  - Patients may have an option in schedule & food
  - All staff are viewed as caregivers & develop skills in respectful communication and teamwork
  - Health Literacy is a part of patient care
  - Information is openly shared with patients
-

# Doing With

---

“We talk together”

“We are on a journey of health & healing”

- Characterized by:
    - Partnerships
    - Mutual understanding based in health literacy
  - Patient/family knowledge & beliefs honored
    - Recognized as an enormous resource for health & healing; as a source of simple solutions
    - Patient determined outcomes
  - Shared knowledge
  - Person- and relationship-based not professional- or organization-based
  - Patient/family as source of control
  - Requires dramatic changes in leadership, culture, systems, and definitions of roles
-

# Doing With

---

You know you are *doing with* when:

- Recognized Doing *for* behaviors as inconsistent with health & healthcare
- Patient/family advisors are on teams to:
  - Design or improve programs that follow the patient journey
  - Teach staff to communicate effectively
- All key decisions are mutual – even when we disagree
- Patients/families are partners in care at every level as they choose
- Senior leaders model that patient's safety & well-being guide all decisions
- Staff, providers, leaders are recruited for values & talent; patient/family advisors involved in hiring practices

# Doing With

---

You know you are *doing with* when the “No List” is eliminated through patient/family partnerships:

- *Patient-Centered* – no helplessness in those served or serving
- *Safe* – no needless harm or deaths
- *Effective* – no needless pain or suffering
- *Timely* – no unwanted waiting
- *Efficient* – no waste for anyone
- *Equitable* – for all

» Modified from the Institute for Healthcare Improvement

# The Next Stage

---

The next stage is being defined today by creative and courageous people who say we can move beyond *Doing With*

It may be –

Patient or Community Driven Care

Health and health care that involves many beyond healthcare professionals

Or what you are working on now . . .