



## THEME 5: HOW PATIENTS AND FAMILIES CAN EFFECT CHANGE An Organizations Point of View

### Nothing About Me Without Me

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### *DANA-FARBER ADMITS DRUG OVERDOSE CAUSED DEATH OF GLOBE COLUMNIST, DAMAGE TO SECOND WOMAN*

When 39-year-old Betsy A. Lehman died suddenly last Dec. 3 at Boston's Dana-Farber Cancer Institute, near the end of a grueling three-month treatment for breast cancer, it seemed a tragic reminder of the risks and limits of high-stakes cancer care. In fact, it was something very different. The death of Lehman, a Boston Globe health columnist, was due to a horrendous mistake: a massive overdose of a powerful anticancer drug that ravaged her heart, causing it to fail suddenly....

The Boston Globe 3/23/1995

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### Key Learning in Journey

- The responsibility and power of all leadership [trustee, clinical and administrative] over safety throughout the ten years
- The need for relentless vigilance to safety, risk, error, near-miss, harm
- Addressing the multiple victims of error
- The crucial role the design of systems and application of technology play in support of safe practice by excellent staff
- The synergy of interdisciplinary practice and team work
- Patient and Family Centered Care

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## Patient and Family Centered Care



- Mainstreamed patient and family centered care model
- Adult and Pediatric Patient and Family Advisory Committees (10 years and 8 years)
- Patient and family participation in operating committees, as well as in all design, measurement, assessment, and improvement efforts
- Endless gifts and an awesome partnership

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## Partnerships With Patients and Families



- Treated as partners in care design, delivery, assessment, and improvement
  - ❖ *"Nothing about me, without me"*
- Can DO tell us things that we don't know
- Can DO make significant contributions to improving our prioritization and work processes
- Are critical in answering the question, is this change an improvement?

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## Patient and Family Centered Care



- People are treated with dignity and respect
- Healthcare providers communicate and share complete and unbiased information with patients and families in ways that are affirming and useful
- Patients and family members build on their strengths by participating in experiences that enhance control and independence.
- Collaboration among patients, family members, and providers occurs in policy and program development and professional education, as well as in the delivery of care

*Institute for Family Centered Care*

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## Tension for Change



- Pediatric experience
- Responding to/learning from a sentinel event
- Longwood Integration of DFPCC
  - ❖ you are changing the system that keeps me alive

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## So, What Do We Do?



- Surveys and focus groups not enough
- Establish an ongoing process that has patients and family members as active participants in care design, measurement, assessment, and improvement--BHAG
- Get leadership buy-in: Board, CEO
- Get help--this is tough stuff and we don't know how to do it

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## Leadership



- Not the sole purview of patient relations or social work
- Nursing and MD leadership must be seen as key leaders of this effort
  - ❖ their buy-in; staff buy-in
  - ❖ ability to influence the "way we do the work"
  - ❖ respects reality of where the work actually must get done
- CEO/COO visible but shouldn't dominate

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## Overarching Structures & Processes



- Committees:
  - ❑ Board Quality Committee
  - ❑ Patient Safety Committee
  - ❑ Strategic Planning
  - ❑ Operating
- Leadership Interviews
- New Employee Orientation
- Side by Side
- Resource Centers
- Rescue events
- NPSF & IHI meetings



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## Adult Patient and Family Council Dana-Farber / Brigham and Women's Cancer Center



- Rounding
- New patient access
- Task Force on Disclosure
- Renovations / Process Redesign
- Advocacy Days
- Working on the Wait
- Customer Service Training
- Falls Task Force

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## Pediatric Patient and Family Council Dana-Farber / Children's Hospital Boston Cancer Center



- ER Fast Track
- End of Treatment
- Renovations / Process Redesign
  - ❑ Patient Flow
  - ❑ Out-patient
  - ❑ In-patient
- Insurance
- Diversity

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## Any Problems / Issues?



- Oh, my, my! This is not work for the meek
- Testing challenging for the first year.
  - ❖ “token, nice, window dressing”
- Very difficult discussions
- Not all staff are at the same place
- Not all patients/families at the same place
- Not clear: what’s on and off table.
- Diversity of membership
- We plan and talk to much, and don’t listen

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## Dealing with Perceived Risks



- Aged mental models
- Unreasonableness
- Time and attention
- Transparency
  - ❖ Disclosure
- Confidentiality of discussions
  - ❖ Rounding
  - ❖ Meetings

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## Barriers



- Attitudinal: Fears, perceptions, beliefs
- Education and understanding
- Organizational vision, culture, leadership, ethics.

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## Key Learning



- We don't know what happens daily in our hospitals.
- We don't know what patients and family members want and need—we don't see through their eyes.
- Patients know the hand-off better than we ever will.
- Patients, families, and staff have many common goals and can work to achieve dramatic improvements.
- We can't forget these are patients, going through extraordinary ordeals.
- Patients want to give back, be involved, contribute to success. They are vested.

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## Key Learning



- Errors don't erode trust. The way we act can.
- We are not asking patients, nor do they want, to run our facilities. Leadership must be visible, involved, and honest.
  - ❖ it takes more than a few years to make it "stick"
- "Don't try to fix it all today. Take small bites and build on successes [rapid cycle improvement]"

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## Benefits / Cost Avoidance



- Core of pro-bono consultants
- Rapidly growing patient volume at a time of dramatic change
- Getting it right the first time [cost of poor quality]
  - ❖ service delivery
  - ❖ facility planning
- Real-time change measurement
- Positive differentiation of care system
- Risk Management

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## Eliminating Excuses



### But My Patients and Families are....

- > Violent
- > Illiterate
- > Undocumented
- > Psychotic
- > Uneducated...
- > .....and so much more

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## Our Vision Is Clear



Care that is reliably:  
*Safe, Effective, Patient  
Centered, Timely,  
Efficient, Equitable*

[IOM, Crossing the Quality Chasm]

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## References



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  - ◊ Key Learning Paper: <http://www.dana-farber.org/pat/patient/patient-safety/docs/journey.pdf>
- > Institute for Family Centered Care [www.familycenteredcare.org/](http://www.familycenteredcare.org/)
  - ◊ This is THE go-to place for this work
- > AHA Strategies for Leadership: Patient and Family Centered Care
  - ◊ <http://www.aha.org/aha/issues/Quality-and-Patient-Safety/strategies-patientcentered.html>
- > Institute for Healthcare Improvement [www.ihl.org](http://www.ihl.org)
  - ◊ Partnering with Patients and Families to Design a Patient- and Family-Centered Health Care System: A Roadmap for the Future
- > Economic and Social Research Institute [www.esresearch.org](http://www.esresearch.org)
  - ◊ Patient centered care for underserved populations, 1/2006

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