Let’s Talk!

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Who We Are

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Engaging Patients ... from the start

Why we do it...

Engaging Patients ... from the heart

mame
mothers against medical error
Lewis Blackman

1985-2000

Lewis Blackman

- Healthy 15-year-old develops severe upper abdominal pain while on NSAID and narcotic pain regimen following elective surgery

- Nurses and residents fail to act upon increasing signs of instability, including 24 hours with no urine output and four hours with no BP

- Lewis dies four days post-op. Autopsy shows a giant duodenal ulcer and 2.8 liters of blood and gastric secretions in the peritoneal cavity
Our Goals

• Informed consent
• Resident supervision
• Care coordination
• Medication safety
• Timely, accurate diagnosis
• Rapid response and critical care training
• Full disclosure of medical error
• Learning from mistakes

Our Journey

♫ The case
♫ The issues
♫ The hospital
♫ The state
♫ The network
♫ The infrastructure
♫ The narrative
Lewis’s Legacy

- Lewis Blackman Patient Safety Act
- Lewis Blackman Chair of Clinical Effectiveness and Patient Safety
- Lewis Blackman Patient Safety Champion Awards
- Lewis Blackman videos
- SC Hospital Infection Disclosure Act
- MAME patient training
- Using patient stories

Maureen Bisognano

The most successfully innovative organizations are “humble and relentlessly patient-centered.”

Is that a surprise?
Patient Engagement ...

questions and concerns

- What does patient engagement mean?
- What works?
- What is the role of the provider?
- What exactly are we trying to achieve?
- Where are the gaps?
- Morality vs. clinical effectiveness
- What is the basis for our policies?

Patient Engagement is not...

- Solely about patients doing their own research online
- Solely about technology and the electronic medical record
- Solely about the doctor-patient relationship
- A way to adapt the patient to the system
- Email
- HCAHPS
Patient engagement is...

Patient engagement is an activity that involves a series of proactive and calculated actions between providers and patients. Actions should be taken based on patient data, population health data and evidence-based best practices. Patient engagement activities positively affect the quality of care received and ultimately improve outcomes.

- Institute for Health Technology Transformation

Patient engagement is...

Properly done, patient engagement in action looks like shared responsibility between patients (and their families if applicable), health care practitioners (the entire team: surgeons, physicians, nurses) and healthcare administrators (providers of the infrastructure and payment models) to co-develop pathways to optimal individual, community and population health. Patient engagement brought to life means involving patients and caregivers in every step of the process, providing training or financial support if necessary to their participation.

- Donna Cryer, CEO, CryerHealth
Patient engagement is...

CFAH defines patient engagement as "the actions we take to benefit from the health care available to us."

- Jessie Gruman, Center for Advancing Health

Common Themes

- Active participation
- Long-term relationships
- Patients AND providers
- Evidence-based care
What Matters

- Listening
- Talking
- Respecting
- Caring
- Avoiding harm

Patterns in Patient Stories

- Lack of respect for the power of medications
- Overconfidence in the benefit of medical treatments and minimizing of potential harms
- Dismissal of patient deterioration as “anxiety”
- Giving psychiatric label to patients with difficult-to-diagnose illnesses
- Certain drugs and procedures
- “Alternate reality”
Reasons?
a patient’s perspective

• Fragmentation
• Poor institutional memory
• Corporate diffusion of responsibility
• Resilience of culture
• Lack of accountability
• Lack of respect for the patient

Solutions?
a patient’s perspective

• Transparency
• Patient Involvement
• Patient Tools and Education
• Listening
• Rapid Response
• Disclosure and Learning
Transparency

Numbers that are meaningful to patients:

• Experience, outcomes, and complication rates
• Specific to
  ✓ Procedure
  ✓ Facility
  ✓ Provider
  ✓ Patient

Patient Engagement ...

wish list

• Informed decision-making
• Navigational tools
• Bedside rounding/Bedside change of shift
• Patient-activated rapid response
• Patient-centered discharge
• Patient-reported outcomes
• Respectful treatment of adverse events
• Patient committees/Patients on boards
• Someone to call
## Patient Tools and Information

- Navigating the system
  - Managing the hierarchy
  - Keeping a record
  - Danger signs

- Patient-specific information
  - The reasoning behind patient treatments
  - What could go wrong
  - What to do in an emergency

### AHRQ

**The Guide to Patient and Family Engagement**

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1: Working With Patients and Families as Advisors</td>
<td>Implementation handbook accompanied by 14 tools in four topic areas: Patient and family advisor recruitment, advisor information session, advisor training, and health care professional training.</td>
</tr>
<tr>
<td>2: Working With Patients and Families at the Bedside: Communicating to Improve Quality</td>
<td>Implementation handbook accompanied by six tools (patient and family tools and clinician training) designed to promote better communication during the hospital stay.</td>
</tr>
<tr>
<td>3: Working With Patients and Families at the Bedside: Nurse Bedside Change of Shift Report</td>
<td>Implementation handbook accompanied by three tools (patient and family tools and clinician training) designed to help hospitals implement bedside shift report. Includes a staff training video.</td>
</tr>
<tr>
<td>4: Working With Patients and Families at the Bedside: IDEAL Discharge Planning</td>
<td>Implementation handbook accompanied by five tools (patient and family tools and clinician training) to help hospitals encourage patient and family engagement around discharge.</td>
</tr>
</tbody>
</table>
Anthony DiGioia’s patient and family centered care

- Shadowing
- Writing the Ideal Story
- Patient Involvement
- Teamwork

http://www.pfcc.org/
The “seven pillars” of the principled approach to adverse events

- Education and Training
- Adverse event reporting
- Investigation
- Communication and Disclosure
- Apology and Remediation
- Process Improvement
- Data Tracking and Performance Evaluation

Engaging Patients....
The Connecticut Center for Patient Safety works to
Promote patient safety
Improve the quality of health care &
Protect the rights of patients.

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Our journey

• 2005 Formed our own not for profit

Why patients get involved

• Gus: double amputee- at 31
• George: 5 year old daughter died –tubal ear surgery
• Steve: wife died overdosed at an allergist – no epinephrine was available. Her two children present
• Hope: daughter died of an infection following c-section. Two children lost their mother
• **10% of deaths in this country are the result of health care harm**

Rosemary Gibson, formerly of the Robert Wood John Foundation and author of two books said that the latest statistics grossly underestimate the scope of the problem. She believes that 250,000 preventable deaths a year from health care harm. 100,000 from error, 100,000 infections, 19,000 unnecessary surgery, 15,000 radio over exposure and the remaining from medication interaction – chaotic prescribing.

**Connecticut Center for Patient Safety**

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**Sydney, Rocky Hill, Birth Injury**

**Connecticut Center for Patient Safety**
Jennifer Manganello, Newington, Deceased, Victim of malpractice and HAI

Connecticut Center for Patient Safety

Dr T. Stewart Hamilton, Deceased, victim of HAI

Connecticut Center for Patient Safety
### National network of activists

- Stop Hospital Infections
- Safe Patient Project
- ProPublica
- Institute for Healthcare Improvement
- Community Catalyst
- NEVER – Northeast Voices for Error Reduction
- MITSS (Medically Induced Trauma Support Services)

### Selling Sickness

- Woody Matters
- First advocate driven national and international meeting bringing together advocates, academics, investigative journalists
- February 2013
Learning curve on solutions

- Impressive work in Maryland – the checklist
- Healthcare Performance Improvement
  – Engineering safety analytics applied to healthcare teamwork, safety huddles.
  some hospitals have seen error cut in half

But we are left with a real problem in a rapidly changing delivery system

Patient participation

PCORI  
Patient Centered Outcome Research Institute
Will help people make informed health care decisions, improve delivery and outcomes by producing evidence-based information that comes from research guided by patients, caregivers and a broader health community.

Consumers help decide what to research and sit on review panels
AHRQ

• This notice announces the intention of the Agency for Healthcare Research and Quality (AHRQ) to request that the Office of Management and Budget (OMB) approve the proposed information collection project: “A Prototype Consumer Reporting System for Patient Safety Events.” In accordance with the Paperwork Reduction Act, 44 U.S.C. 3501-3521, AHRQ invites the public to comment on this proposed information collection.

A few other changes

• Hospital mergers
• Accountable care organizations
• Medical Homes
• 80% surgeries - ambulatory care
• Aging population

Where does that leave us?
What we are trying

• Outreach educational programs to nurses, doctors and professional associations.

• Gus Velez story

The problem

• How do we SPREAD the known solutions to turn islands of excellence into the norm?
• How do we engage patients in the solution?
• What are the barriers for both providers and patients?
• What tools do both patients and providers need?
What patients would like

• To be heard
• Strong provider relationships
• Individualized care
• Understanding of patient needs and circumstances
• Skill building and problem solving
• Follow up contact
• Integrated health system

What we want from you

• Improve care thereby reducing harm and cost

• Provide necessary leadership to implement team approach to care provision

• Continue the dialogue with patients
And what we believe

• Perseverance

• Hope

– Each one of us can make a difference

WHO—World Health Organization

LONDON DECLARATION
Patients for Patient Safety
WHO World Alliance for Patient Safety

We, Patients for Patient Safety, envision a different world in which healthcare errors are not harming people. We are partners in the effort to prevent all avoidable harm in healthcare. Risk and vulnerability are constant companions. We work together to promote a culture of prevention and learning, so that people everywhere can receive care without harm in the developing as well as the developed world.

We are committed to spread the word from person to person, town to town, country to country. There is a right to safe healthcare and we will not let the current culture of error and denial continue. We call for honesty, openness and transparency. We will make the reduction of healthcare errors a basic human right that preserves life around the world.

We, Patients for Patient Safety, will be the voice for all people, but especially those who are now unheard. Together as partners, we will collaborate in:

• Developing and promoting programs for patient safety and patient empowerment.
• Enhancing and driving a constructive dialogue with all parties concerned with patient safety.
• Establishing systems for reporting and dealing with healthcare harm on a worldwide basis.
• Defining best practices in dealing with healthcare harm of all kinds and promoting those practices throughout the world.

In honor of those who have died, those left disabled, our loved ones today and the world’s children yet to be born, we will strive for excellence, so that all involved in healthcare are as safe as possible as soon as possible. This is our pledge of partnership.

March 29, 2006
We all have a story.....

• June 2006 surgery for a right ankle replacement
• At Pre-op appt. was given a bottle of something and told to wash with it before the surgery – NO ONE EXPLAINED WHY THIS WAS SO IMPORTANT
• No information about surgical site infections, MRSA, etc..
• NO ONE asked does anyone in your family have (or has had)MRSA
Missed Opportunities

- If anyone mentioned MRSA at all
  - Would’ve have told them about my son who moved home 3 months earlier for me to pack his open wound – his infection was MRSA
  - If I had known the implications, I would’ve pushed CVS to give me enough medication to last to Monday when they could work it out.

Fast Forward

August, 2012

Ventral Hernia Repair
**GREAT Patient Handouts**

- Are you asking patient and/or families if they understand it?
- Is it just another check box item for you?
- Where is the engagement?
What MITSS hears...

- I kept telling them something was wrong, but no one listened..
- We didn’t get the truth...
- I want to get involved with the hospital to work on safety issues.
- I have to have more surgery, but now I am scared to death.
- Every time we get calls from family members, the theme is the same –
- they live with the “Should’ve, Could’ve, Would’ve”

Patient Harm

- How are you engaging patients that have been harmed?
- How is your organization engaging patients who have been harmed?
- Are you involving patients in the RCA?
- When appropriate, are you asking patients and their families what their perception of what happened is?
NOT Patient Engagement

“Patient engagement is increasingly recognized as a core driver toward a high performance health system.”
"The lack of patient engagement is the Achilles Heel of health care delivery."
Adapted from quote by Terry McGeeley, MD

The problem is not so much that patients are unengaged...but rather that providers are not always very engaging

Copyright Smart Health Messaging

Engaging Patients ... together

From the Waiting Room to the Boardroom....
Engaging Patients ... Let’s talk!

- In what ways is your hospital engaging patients?
- What do you see as barriers?
- How effective is it?
- How can we help you?
- What are some of your ideas?
- Share your success stories!

Can you define what patient engagement is NOT?
*Assume* that patients will bring value
Focus on reducing barriers
Include patient(s) in planning phase
Look for models of excellence* (maternity, NICU, other facilities)
Train patients reps AND staff/committee members
Assign a mentor
It’s the questions, not the answers that matter most
Measure your outcomes! “How’s it going?”
Spread the word
What else??

Engaging Patients **YOU can do it!**
Never doubt that a small group of thoughtful, committed patients can help improve the system. Indeed, with your help & leadership, it is happening every day.

THANK YOU!

Thank you Margaret Mead

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