Moving Outside the Boundaries of the Doctor's Office

“The Impossible Dream”

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Our Perspective On A Broken Healthcare System
My Background

- Bachelors Degree in Medical Technology
- Bachelors Degree in Nursing (Med/Surg, Cardiac, ICU)
- 30 + years in Health Care
- Almost 30 years of bedside nursing
- Heavily involved in in-patient patient safety activities
- Served as Clinical Trials Nurse/Coordinator
- Spoken Nationally on Patient and Family Engagement
- Member of Patient and Family Advisory Council for Quality and Safety
Jerod's Health Care Journey...

- Routine physical in August 2011, was asymptomatic and felt in perfect health; only complaint – minor low back pain
- PSA in 2009 – 1.29
- PSA in 2011 – 535 (yes, 535)
- Biopsy: Gleason 8 (4+4) (positive 3 of 12 core samples)
- Stage IV prostate cancer at diagnosis with significant bone metastases
- Standard androgen deprivation therapy - failed at 3 months
- Local oncologist – next option to offer was “what insurance would cover”, not what would be the best treatment
• After prodding by us off-label use of abiraterone at an out of pocket cost of $6,000/month – No suggestion of clinical trial

• Enrolled in clinical trials at NIH Clinical Center in Bethesda, Maryland and the MD Anderson Cancer Center in Houston, Texas; monthly trips to Houston
“Try to focus less on a cure and more on a treatment you can afford.”
We Have Seen The Best Of Health Care And The Worst Of Health Care….

- Drugs that work and then stop working
- Physicians who prescribe drugs that should not be prescribed together
- Dispensing errors; failures to accurately reconcile medications
- The interesting phenomenon of being hurt in order to be helped
- Unanticipated drug-drug interactions
- Forgetting to be told the results of significantly abnormal laboratory results
- Almost never being given good news without the inevitable "but" that all cancer patients can associate with
- An association with several oncologists who care and are extraordinary role models - and some who are not

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Patient-centered care supports active involvement of patients and their families in the design of new care models and in decision-making about individual options for treatment. The IOM (Institute of Medicine) defines patient-centered care as: "Providing care that is respectful of and responsive to individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions."

Donald Berwick MD, MPA
Making Individual Health Care Decisions Can Be Hard – Even With Good Evidence And Even For Someone In The Field For Many Years

Technical Quality Is Important - But So Too Is Patient Experience Of Care
Research Letters

ONLINE FIRST

Communicating With Physicians About Medical Decisions: A Reluctance to Disagree

Jared R. Adama, MD, PhD; Glyn Elwyn, MB, BCh, MSc, FRCGP, PhD; France Légaré, MD, PhD, CCFP, FCFFP; Dominick L. Frosch, PhD

[+] Author Affiliations


Published online July 2012
Percentage of participants who would ask questions of, discuss preferences with, or express disagreement to their physician when relevant.
Some “Loeb Maxims” To Remember

What We Have Learned In The Last 24 Months......
…But Choose Your Health Care Provider Even More Carefully

- Not all physicians or hospitals have the same expertise
- Ratings (hospital and physician), while ubiquitous, are often irrelevant, and many times, just wrong
- Access to innovative care depends on innovative caregivers with innovative knowledge and awareness
- Patient’s values and desires matter, especially when the evidence runs out as it often does in cancer
- Interdisciplinary vs. multidisciplinary
Patient and Family Engagement

A set of beliefs and behaviors by patients, family members, and health professionals and a set of organizational policies, procedures and interventions that ensure both the inclusion of patients and families as central members of the healthcare team and active partnerships with providers and provider organizations.

Benjamin K. Chu, M.D. Chair of the AHA’s Board of Trustees
Surviving A Health Care Crisis Requires Having A Relative/Friend With You At All Times

- Even health care professionals become deaf, dumb and blind when in crisis mode about their own health
- Navigation of the health care system requires a map, a guide, and an extraordinary amount of skill and stamina – even for those who work in the system
- And that is before you have to deal with insurers

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Communication Failures Are The Rule And Not The Exception

• Literacy levels are low.....and health literacy levels are even lower
• Communication failures at transitions of care are nearly ubiquitous.....and harm patients every day
• These failures occur between physicians and physicians, physicians and nurses, nurses and nurses, and between all types of caregivers and patients
I’m Clear, You’re Clear, We’re All Clear:

Improving Consultation Communication Skills in Undergraduate Medical Education

• With increased attention on transitions of care in light of the recent scrutiny of duty hours, consultations and other interphysician interactions, such as handoffs, are becoming increasingly important. As modern medicine increases in complexity, the skill of communicating with medical colleagues throughout the continuum of care becomes more challenging.

Academic Medicine, June 2013 - Volume 88 - Issue 6 p 753-758 Kessler, Chad S. MD, MHPE; Chan, Teresa MD; Loeb, Jennifer M.; Malka, S. Terez MD
Shared decision making ...

...is an approach where clinicians and patients communicate together using the best available evidence when faced with the task of making decisions, where patients are supported to deliberate about the possible attributes and consequences of options, to arrive at informed ...

http://en.wikipedia.org/wiki/Shared_decision_making
The Next Generation…

- …..of health care professionals is our only hope
- We need to stop producing square pegs for round holes
- Tinkering with the system will not fix the problems with the system
- Apology, disclosure, teamwork, collective mindfulness, high reliability systems, and elimination of variation will go a long way toward helping improve quality and reduce the risk of adverse events
The Actual Next Generation
“I have the distinct feeling that the patient in America is becoming invisible. She is unseen and unheard....I gently insist that we go to the bedside, but that is often a place where the team is no longer at ease. I realize what has happened: the patient in the bed is merely an icon for the real patient in the computer.”

A. M. Nussbaum, MD
A Piece of My Mind
JAMA
July 17, 2013
A Cynical Mantra

• Educate the young

• Regulate the old

• Hope the rest retire or die off

With Thanks To David Mayer, MD
First Hospitalization in Houston Cancer Center – January 2013

- 100% Hand Washing
- Phenomenal Communication – White boards in ED and Inpatient Rooms
- Bedside Handoff Report between RN’s
- Patient Centered Compassionate Care
- Shared Decision Making
- Patient and Family Engagement
- Team Approach
- Excellent Transitions in Care
- Patient Safety Key in all areas of care
Local Hospitalization

- July 2013

- Missing vital signs
- No patient assessment
- Bypassing of CPOE alarm system (audible and visible)
- No communication among caregiver(s) and patient/family members
- No communication among physicians
- Lack of hand hygiene
- Lack of patient identification
- Absence of Shared decision-making Picc line experience

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“I think there is a revolution coming. In the past, patients were expected to be obedient and compliant.”

Harlan M. Krumholz, MD, SM
Yale School of Public Health
July 2013
Front-Line Lessons

- The power of friendship triumphs
- Care is not the same from MD to MD or from HCO to HCO
  - ★ Patients should not be compared
- Nursing and compassion are not the same
- Standard of care may be perfect for some - but not for all
- Importance of leadership, leadership, leadership
- Patient and family engagement means everything
- Hiring the right employees is key

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Recent Experience With Hospice/Palliative Care

- Patient Centered Compassionate Care
- Shared Decision Making
- Patient and Family Engagement
- Genuine Love For Profession
- Treated Patient Not Disease
- Knew The Ultimate Outcome But Never Ever Lost The Passion For Caring
- Knew When It Was Time To Prepare For The End
- Treated The Family Not Just The Patient
Reasonable Expectations That Patients Who Are Seriously Ill Deserve To Have Fulfilled:

- To have one’s pain and other physical symptoms regularly assessed and competently treated.
- To have adequate information about one’s condition and treatments, in clear and simple terms.
- To have care coordinated between visits and among physicians and health programs involved in one’s care.
- To have crises prevented when possible and have clear plans for managing emergencies in place.
- To have enough nurses and aides on staff in hospitals and nursing homes to provide safe and high quality care.
- To have one’s family supported in giving care, in their own strain and, eventually, in their grief.
• You treat a disease, you win, you lose. You treat a person, I guarantee you, you’ll win, no matter what the outcome.

• Our job is improving the quality of life, not just delaying death.

• We need to start treating the patient as well as the disease.

• You actually are a doctor and admitted it, you’d say, “I don’t cure a huge percentage, I don’t have a 50 percent cure rate...(but) I can have a 100 percent compassion rate.”

Hunter “Patch” Adams MD 1998
Some May Wonder Why Physicians Keep Trying Different Meds and Different Treatments When Many Think The Situation Is Hopeless......

But Have They Asked The Patient, Because That Is Where The Real Answer Lies?

Our First Family

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Our Second Family

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Our Third Family
...”But Never, Ever, Take Away Hope....”

LaMar S. McGinnis, Jr., MD, FACS
Member, The Joint Commission Board of Commissioners
Former President, American Cancer Society
Former President, American College of Surgeons
Thank You For Allowing Me To Share Our Story!
In Loving Memory of Jerod