

National Health Care Ratings Summit

December 7, 2017

Closing Reflection

Beth Daley Ullem



October 18, 2003



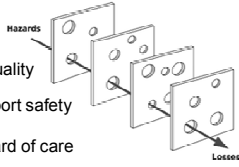
2003 ...The Ultimate 'Bad' Care

- I lost my son, Michael, to preventable medical error
- My eyes opened to the extent of the challenges in the systems and processes of good patient care



Drivers of the harm that killed my son

- Culture of blame, not learning
- Leadership did not 'own' safety and quality
- Technology not used properly to support safety
- Policies out of compliance with standard of care
- Highly variable handoffs and transitions of care
- Overreliance on and poor oversight of residents



So, in 2004 I began to ask myself how to...

- Measure safety and quality and be able compare results across institutions
- Build the 'business case' for safety
- Create a high reliability culture of transparency, learning and improvement as seen in other industries
- Establish better oversight of safety and quality at the board level and link to hospital leader incentives

Life throws a curveball....

20 week In Utero
Diagnosis:

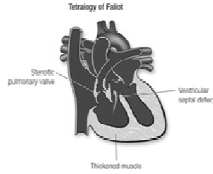
Tetralogy of Fallot
(TOF)



Tetralogy of Fallot

4 part heart defect:

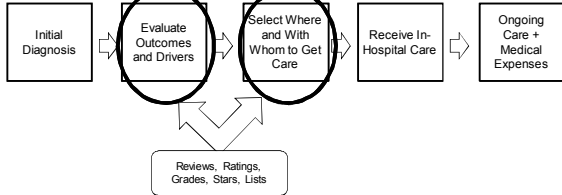
- 1) VSD - Ventricular septal defect (hole in heart)
- 1) Thick right ventricle (hypertrophy)
- 2) Right overriding aorta (wrong spot)
- 3) Narrow pulmonary valve (stenosis)



Source: American Heart Assoc.

Patient Continuum -Diagnosis to Receipt of Care

Patient's Mind...

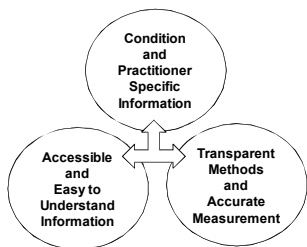


Consumers Expect Data Transparency

Today when I buy....I compare data

Buying a Mutual Fund	<ul style="list-style-type: none"> • 1-3-5 and 10 year returns versus the index • Fund top quartile performance • Fees and Returns net of Fees • Manager Turnover
Buying a Car	<ul style="list-style-type: none"> • Price • Safety • Gas mileage • Consumer Reports / Reviews
Buying a New Flat Screen TV	<ul style="list-style-type: none"> • Price • Shipping / Deliver charges • Consumer Reviews

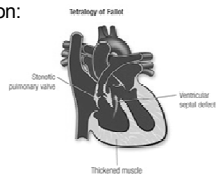
Comparing Data for Health Care Decisions



Tetralogy of Fallot...What Drives a Good Outcome?

Defining a 'good outcome' for my son:

- Variations in surgical approach
- Volume matters
- Collaborative care team (non hierarchical, patient centric)
- Prevent harm – safety metrics
- Transparent, learning culture



Developing my Tetralogy outcome grid:

	Hospital 1	Hospital 2	Hospital 3
Mortality rate			
# Total Cardiac surgeries at hospital			
% of Tot. Cardiac surgeries at hospital that are TOF			
% of Total TOF of hospital that are valve sparing			
# Total Cardiac surgeries of surgeon			
% of Tot. Cardiac surgeries of surgeon that are TOF			
% of Total TOF of surgeon that are valve sparing			
% of TOF repair with Altitude restrictions			
% of TOF repair with Exercise restrictions			

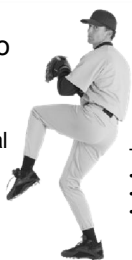
Developing my Tetralogy outcome grid:

Institutional Culture and Safety Data around Harm:	Hospital 1	Hospital 2	Hospital 3
Transparent Approach to A&D (Y/N)			
% Surgical Site Infections out of Total			
Surgeon Time out (Y/N)			
HAC Rate			
Just culture and non-hierarchical (Y/N)			
Respectful of Parents – Open communication (Y/N)			
Oversight of Residents (descriptive) – Ownership of Patient			

Another Curveball....

24 week In Utero
Diagnosis:

Tracheo-esophageal
Fistula (TEF)



- This diagnosis required:
- General pediatric surgery
 - Experienced NICU
 - Top high-risk OB.

Developing my TEF outcome grid:

	Hospital 1	Hospital 2	Hospital 3
# Total Surgeries of Surgeon per year			
% of Total Surgeries that are TEF/EA			
Connected Hospital to a High Risk OBGYN Delivery Facility (Y/N)			
On Site (not on call) Anesthesia (Y/N)			
Level 3 NICU (Y/N)			
% TEF tube fed age 5			
% TEF with exercise restrictions			

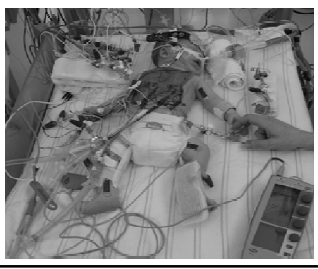
In 2007, the data I found revealed significant variation in outcomes

Sample Findings*:

	Hospital A	Hospital B	Hospital C
% of Total TOF of surgeon that are valve sparing	12%	25%	60%
% of TOF repair with Altitude restrictions	most	50%	10%
% of TOF repair with exercise restrictions	most	50%	20%

Source: 2007 Patient collected data.

Valve Sparing Repair – age 2 ½ months

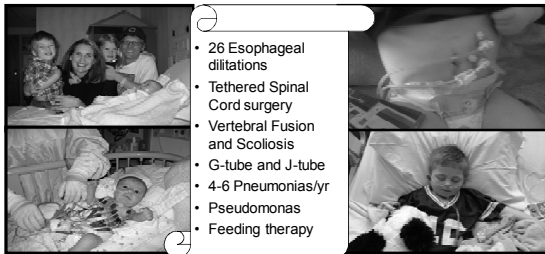


Great outcome – but not without harm

Our Harm events:

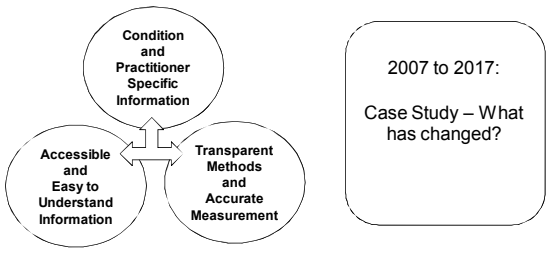
- *Overdosed on Reglan – given 3.0 ml versus 0.3 ml*
- *Contracted VRE (a hospital acquired infection) and went into isolation for 2 months*

Welcome home...to a longer road.



- 26 Esophageal dilations
- Tethered Spinal Cord surgery
- Vertebral Fusion and Scoliosis
- G-tube and J-tube
- 4-6 Pneumonias/yr
- Pseudomonas
- Feeding therapy

Role of Ratings to Help Me Make a Health Care Decision



A 10 Year snapshot: Have we gotten better?

In 2017, I created a case study based on my son's diagnosis (TOF). I asked participants from a variety of socio-economic and language backgrounds to research to get their care based on available outcome information.

Would they be able to get better information and the right information in 2017 to make a more informed choice about patient care than I was able to make 10 years ago?

2017 case study findings

Celebrate the Progress!!

While recognizing that the work ahead is a long road, requiring continued tenacity and collaboration.



Case Study Highlights

Lower education and socio economic



"Collecting data took a long time and I was still not sure if I was looking at things the right way."
"I wish the words were clearer and more simple – we are not doctors."
"I was not sure how they made up the scores like reputation and volume and the scores did not match the other stars I found"

Chose: Texas, Boston, Lurie, Mott
No valve sparing data found
No individual doctor data found
No safety data found

Case Study Highlights

Highly educated and high socio-economic pre med student



"It was easy to find volume, mortality and reputation data on the hospital level. Slightly harder to find safety information"
"However, there was no information about a valve sparing repair or specific doctors that I could find."
"I thought the ratings available were helpful in locating specialty hospitals but not identify a specific doctor."

Chose: Texas, Boston, Cincinnati and Mott (Michigan)
Extensive hospital-level data found from multiple sources: volume, number of CVICU beds, infection rates, mortality

Case Study Highlights

Non-english speaker
Lower socio-economic status



"I don't know how to work a computer well and I don't speak English. Most of the things I found on Google were in English and I did not really understand.

I found this scary and overwhelming and I did not know how to understand the numbers."

Chose: Children's Hospital Orange County, Rady Children's in San Diego, Boston Children's

No data found
Just selected names from Google searches

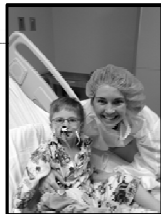
Summary of Patient insights

- 1. Progress!! Information is Better, but not enough...**
- 2. Outcomes Need More Detail** at the clinician and condition level to be more meaningful. Demand for more detail will continue to accelerate.
- 3. Cost is missing** and patients will increasingly expect an outcome/cost/experience integration – cost matrix not available.
- 4. Transparency of methodology** so consumers can choose how they weight the things that are most important to them and boards can evaluate measures relative to other improvement efforts.
- 5. Reviews and Feedback will proliferate** – The 'yelp' mentality will demand that hospitals either be transparent in their patient satisfaction scores (e.g. Utah) or patients will self-publish a less complete set of reviews.
- 6. Health Literacy and Language is a Barrier** to access and decipher information widening the health equity care gap.

The Leadership Test...

Do ratings help a patient to...

- **Guide** them to the right hospital that will provide safe, consistent high quality care for their condition.
- **Assure** them that the hospital will involve them in their own care and give them equal care to other patients.
- **Know** that if harm does happen the patient will be told, the event will be reported and learned from to improve.



Taking stars, rankings and ratings from bedside to boardroom

How to use ratings in the board room?

- Boards are inconsistent in how they evaluate and engage on ratings. How should they integrate the stars, ratings and rankings into their evaluation of their hospital's ongoing work in patient safety, quality and patient experience?
- Many board members have concerns about the pressure to have good ratings to use for marketing. There is concern that the ratings will drive resource allocation or cause patient selection or decisions that are sub-optimal.
- How should our hospital support patients in their information gathering and decision process outside of the ratings?

The Way Forward

Patient-centered
 Condition-specific
 Cost/value matrix
 Transparent methodology
 Support decision guides



Patients like me need you...
 Work together
 Demand Better Care
 Speak for us.