

# The Word That Shall Not Be Spoken

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# My Introduction to “Suffering”

- March 2013 – breakfast with Pat Ryan
- My initial reaction (negative)
- Reaction of my physician colleagues at NEJM (also negative)
- Comment by copy editors that NEJM does not use the word suffering

## The Word That Shall Not Be Spoken

Thomas H. Lee, M.D.

During the years when I worked in an academic integrated delivery system, my colleagues and I would frequently discuss patients' experiences and ways to improve our management of their pain and reduce

eg; from a clinician's perspective, it was obviously the right thing to do.

So it was a pleasant surprise when I studied the business strategy of a company that assesses patients' experiences and found

the word “suffering” would take some getting used to. I couldn't remember the last time that my colleagues and I had used that word. “Suffering” made me uncomfortable. I wondered whether it was a tad sensational a bit too

# A Moment of Discontinuity in Health Care

- We have a crisis in the coordination of care -- throughout the world
- History is happening to us, with the chief irresistible drivers of change being:
  - Medical progress
  - Aging population
  - Global economy
- Challenges for providers and patients:
  - Too many people involved, too much to do, no one with all the information, no one with full accountability
  - Result: Chaos → gaps in quality and safety, inefficiency
  - Patients are afraid not just of their diseases, but of lack of coordination

***Question: If somehow, magically, health care costs were not a problem, would you say that health care is working just fine?***

# What Are We Trying to Do in Health Care?

1. It's hard to become more efficient without understanding what you are trying to be more efficient at doing

- It's not immortality, nor something as simple as health.
- Reduction of suffering
- Coordination of care
- Peace of mind

2. If we are supposed to be producing peace of mind and reducing suffering, how well organized are we to do it?

3. What do we know about the nature of suffering?

- It comes in many forms, and is inherent to being a patient
- It is like a gas that fills the room

# Deconstructing Suffering

## Inherent Suffering

Experienced even if  
care is delivered  
perfectly

**OUR GOAL:**  
**Alleviate** this  
suffering by  
responding to  
Inherent Patient  
Needs.



## Avoidable Suffering

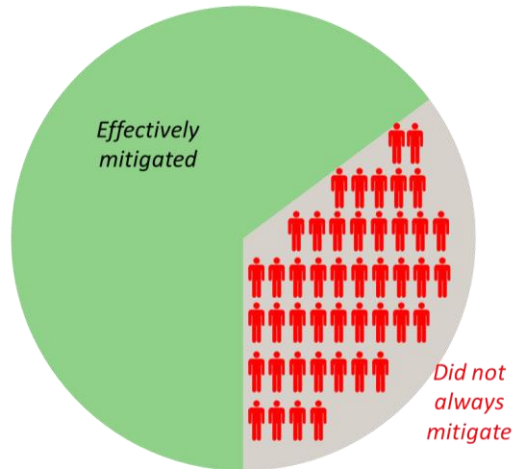
Caused by defects in  
the approach to  
deliver care

**OUR GOAL:**  
**Prevent** this  
suffering for patients  
by optimizing care  
delivery.

# Suffering Is Measurable

## Mitigatable Suffering Arising from Illness & Treatment:

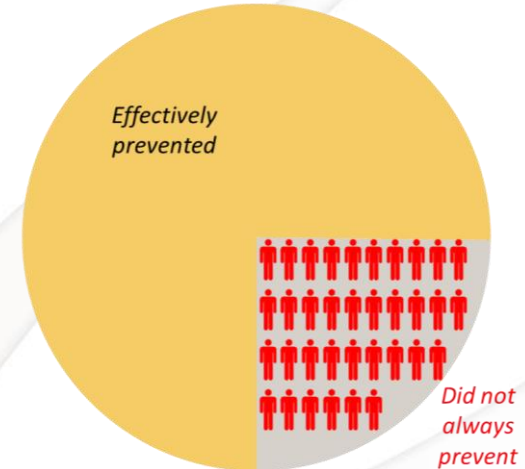
*Communication gaps, pain management, responsiveness, anxiety*



Measure Description	% Top Box	% Sub-optimal
How often did nurses explain things to you in a way you could understand? (HCAHPS)	75.2%	24.8%
During this hospital stay, how often was your pain well controlled? (HCAHPS)	64%	36%
During this hospital stay, after you pressed the call button, how often did you get help as soon as you wanted? (HCAHPS)	64.8%	35.2%
How well did staff address your emotional needs? (PG)	57.5%	42.5%

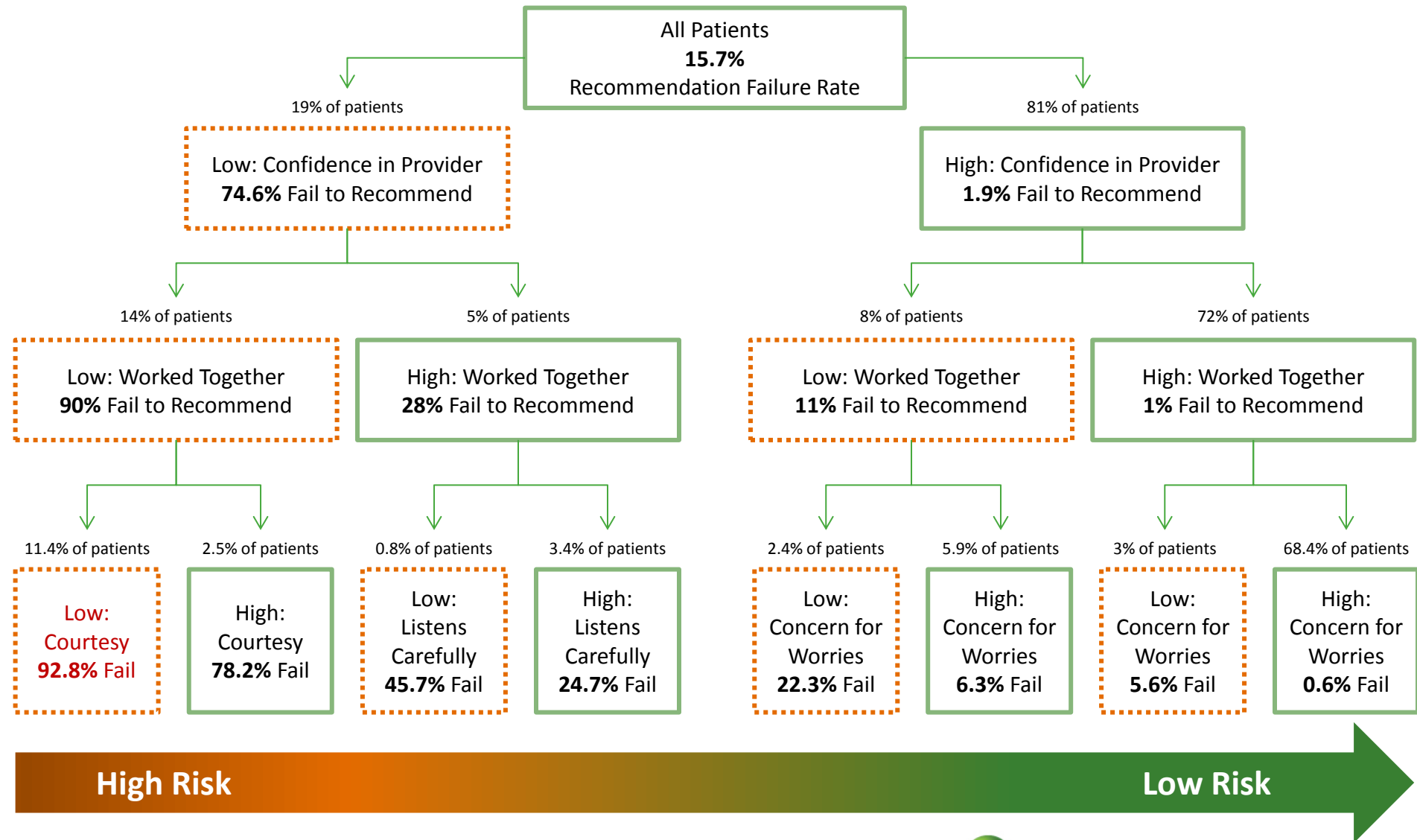
## Avoidable Suffering Arising from Dysfunction:

*Lack of respect, lack of coordination and teamwork, lack of privacy*



Measure Description	% Top Box	% Sub-optimal
How often did nurses treat you with courtesy and respect? (HCAHPS)	85.8%	14.2%
How well staff worked together to care for you (PG)	70%	30%
Staff concern for your privacy (PG)	68.5%	31.5%

# What Do Patients Really Value?



# What Do Patients Want From Physicians?

## An Ounce of Evidence | Health Policy

The blog of Ashish Jha – physician, health policy researcher, and advocate for the notion that an ounce of data is worth a thousand pounds of opinion.



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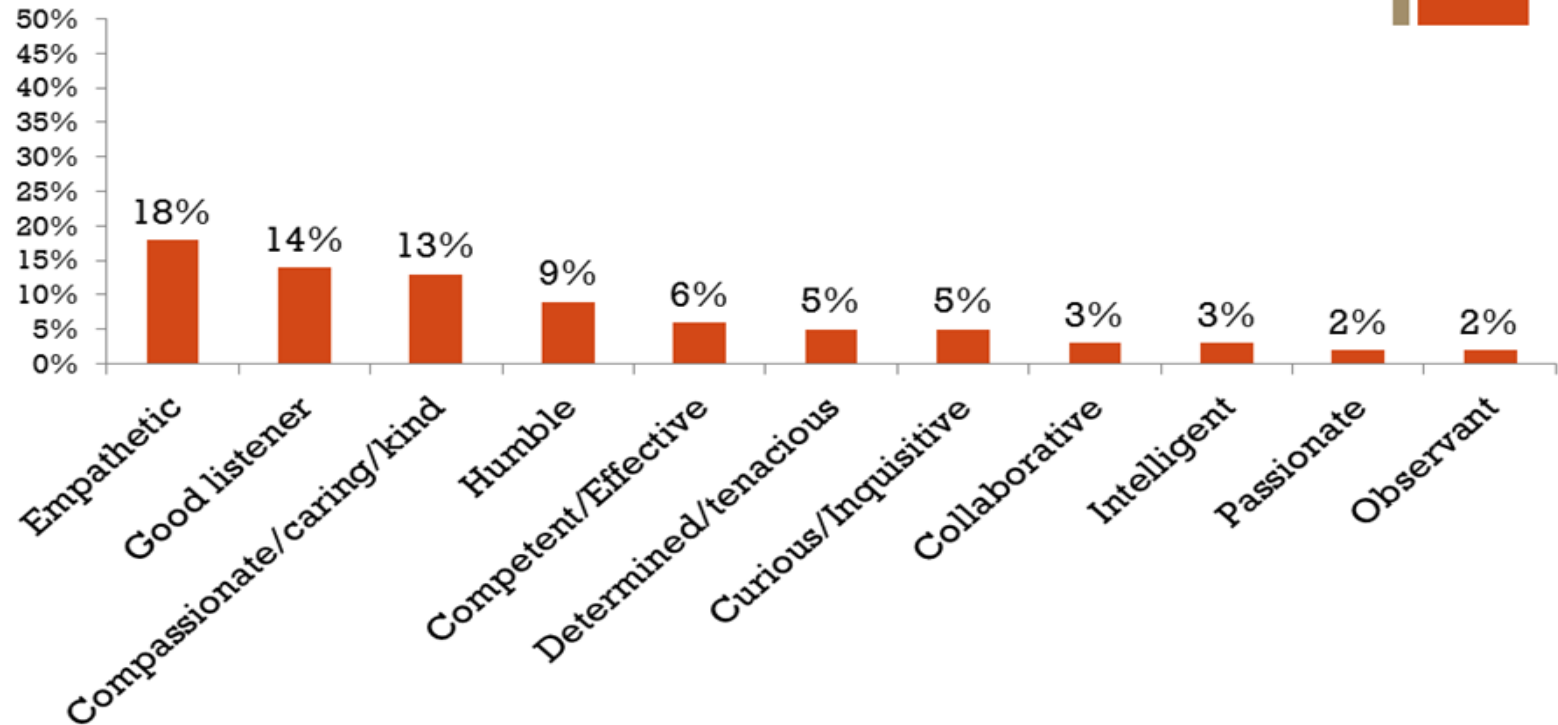
## What makes a good doctor, and can we measure it?

I recently spoke to a quality measures development organization and it got me thinking — what makes a good doctor, and how do we measure it?



# The Top One Word Answers From Twitter

+ Top 10



# Empathy Is Work

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- It's not about how good a person you are
- It's not about internalizing the pain of others
- It is about understanding the needs of others
- And it's about conveying that you understand those needs

# We Know What to Do: “Compassionate Connected Care”

## 1. Acknowledge Suffering

We should acknowledge that our patients are suffering, and show them that we understand.

## 2. Body Language Matters

Non-verbal communication skills are as important as the words we use.

## 3. Anxiety is Suffering

Anxiety and uncertainty are negative outcomes that must be addressed.

## 4. Coordinate Care

We should show patients that their care is coordinated and continuous, and that “we” are always there for them.

## 5. Caring Transcends Diagnosis

Real caring goes beyond delivery of medical interventions to the patient

## 6. Autonomy Reduces Suffering

Autonomy helps preserve dignity for patients

# Example: Body Language Matters

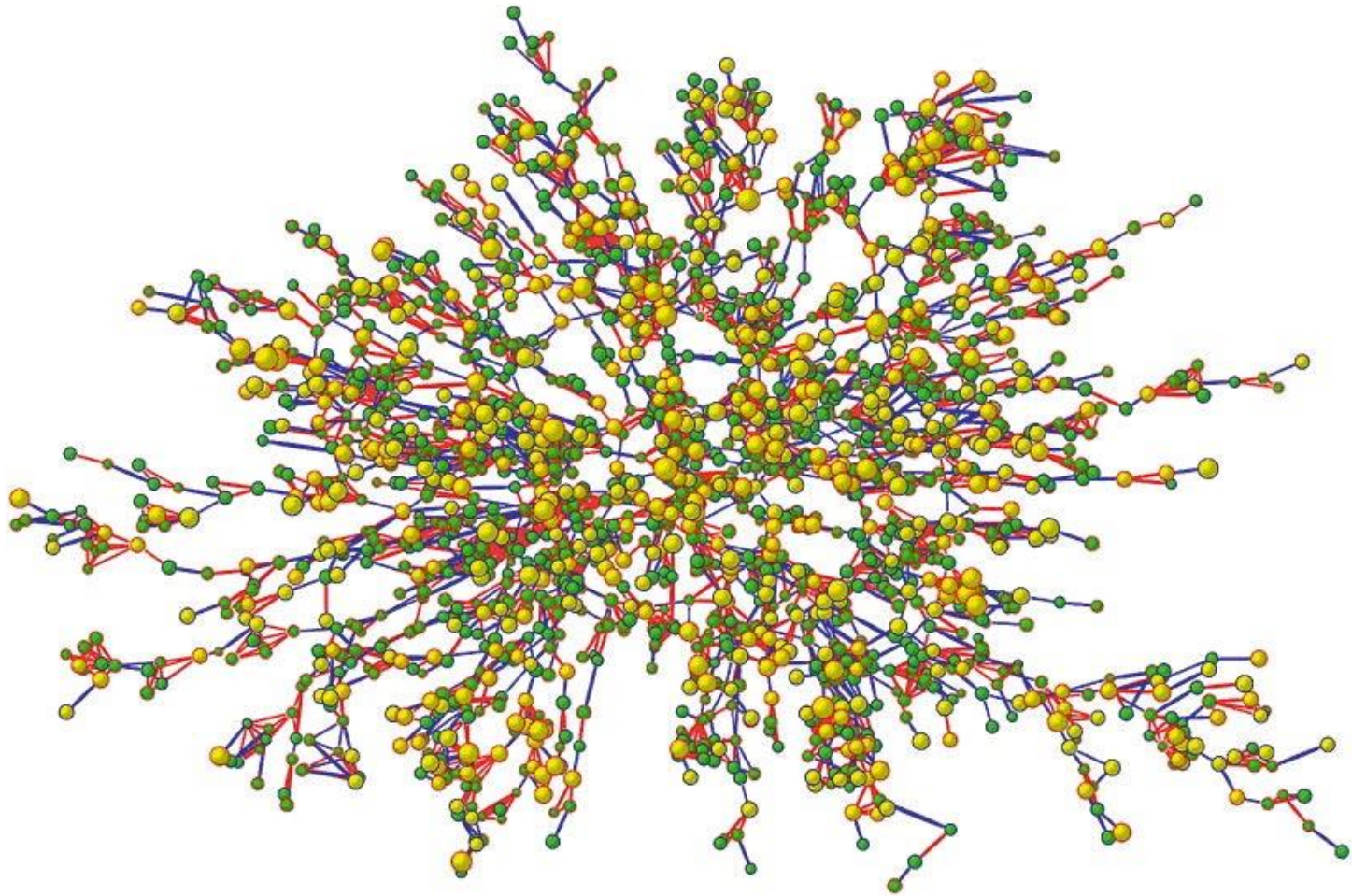
<p>Non-verbal communication skills are as important as the words we use.</p>	<p>1. Eye contact matters</p>	<ul style="list-style-type: none"><li>• The clinician sits at eye level and looks me in the eye during the conversation</li><li>• The front desk caregiver looks up from the computer to establish eye contact</li><li>• As the patient begins to say what is really on his mind, the caregiver pushes his/her laptop aside, leans forward, and listens attentively.</li><li>• Caregiver explains to patient that he/she is listening and is fully engaged with the patient while documenting in computer</li></ul>
	<p>2. Physically touching the patient closes distance</p>	<ul style="list-style-type: none"><li>• The nurse gently held the patient's shoulder while obtaining the blood pressure</li><li>• The physician sat down and held the patient's hand while explaining tests and treatments.</li><li>• The clinician takes a seat and holds the patient's hand when the patient starts to cry.</li><li>• The physician makes a point of shaking hands with the patient and the visitors when introducing him/herself</li></ul>
	<p>3. Body position matters</p>	<ul style="list-style-type: none"><li>• The physician sits face-to-face with the patient while talking with him/her</li><li>• The caregiver sits down at eye level with the patient.</li><li>• The caregiver does not turn their back to the patient until the interaction is over and the caregiver leaves the room.</li></ul>

# “Wordle” From Patient Comments for One MD





# Values Can Spread With Same Patterns as Infectious Diseases



# Can We Create an Epidemic of Empathy?

- Social network scientists have shown that values and emotions can spread in populations in the same patterns as infectious diseases.
- How can we take the practices of our most empathic clinicians and the teams that deliver the best coordination – and turn them from the exceptions to the new norms?
  - Create shared vision
  - Measure
  - Use the other three Weber models for social action
- Turn our social networks into social capital

# What Does It Mean to Organize Around the Reduction of Suffering?

- Agree that this is the overarching goal – and that it trumps the individual agendas of everyone in health care.
- Measure outcomes that matter to patients, including “soft measures” the capture anxiety, confusion, fear, trust, and peace of mind
- Make empathic care the norm, not the exception
- Create incentives (financial and non-financial) for meeting patients’ needs as efficiently as possible.