

# *Patient Safety and Clinical Ethics* *The Patient Perspective*

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## *Overview of Presentation*

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- ❖ Reflect on progress in patient safety 10 years after the IOM report, *To Err is Human*, which launched patient safety efforts
- ❖ Identify patient and family perspectives on a critical aspect of patient safety, the disclosure of adverse events
- ❖ Discuss how patient safety and clinical and organizational ethics go hand in hand

## ***Patient Safety: 10 Years***

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- ❖ In 1999, *To Err is Human* was the first public acknowledgement that preventable adverse events occur in health care
- ❖ The IOM report gave us new vocabulary -- medical errors, patient safety, high reliability
- ❖ It was a collective examination of conscience

- ❖ The IOM report acknowledged the reality of human fallibility in a system of enormous complexity
- ❖ Standard practice was to deny mistakes and preventable harm to patients at an individual and aggregate level

## ***Are We There Yet?***

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- ❖ The Institute of Medicine set a goal of a 50% reduction in errors by 2004

## ***Remember When...***

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- ❖ “We had no idea what to do about the problem.... There was not much in the literature... about what could be done...” Dr. Lucian Leape
- ❖ Since 2000, an abundance of practices to advance safety have emerged: 5 million Lives Campaign, universal protocol, etc .

## ***What Has Changed?***

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- ❖ Improvements have been made in discrete processes of care, e.g. VAP, reducing harm from falls, preventing wrong site surgery, strengthening infection control and prevention
- ❖ Research documents improvements, e.g. 66 percent reduction in central line associated blood stream infections in more than 100 hospitals in Michigan sustained for 18 months
- ❖ A few institutions such as Cincinnati Children's Hospital (with its intranet home page with days since last preventable adverse event with harm) and Virginia Mason have pursued organization-wide transformation
- ❖ Geisinger's 90-day warranty for cardiac care

## ***The Work Continues***

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- ❖ Ensuring safety and reliability over the course of a patient's hospital admission is a continuing challenge
- ❖ Patient safety practices are nascent in non-hospital facilities, e.g. nursing homes, psychiatric facilities, free-standing ambulatory surgery centers, physicians' offices

## ***Disclosure of Adverse Events to Patients and Families***

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- ❖ In health care, we have not had norms, policies or practices to talk to patients and families in the aftermath of an adverse event
- ❖ We have not had norms, policies or practices to talk to *each other* when adverse events occur
- ❖ If communication is rare or non-existent about adverse events among health care professionals, how can conversations occur with patients?

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**“Maybe we need the equivalent of a palliative care team when an adverse event occurs.”**

Source: Participant at a National Board of Medical Examiners session on disclosure of adverse events

## ***Parallels with End-of-Life Care***

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**A brief digression on the conversations about end-of-life care**

**Mortality and fallibility have commonalities: no one wants to talk about them**

## ***Parallels with End-of-Life Care?***

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- ❖ **For many patients facing end-of-life decisions, conversations about their preferences do not take place (SUPPORT, JAMA, 1995)**
- ❖ **Twenty years ago, medical and nursing textbooks rarely mentioned the care of patients at the end of life**
- ❖ **Fast forward to 2009, 1400 hospitals report having a palliative care program or consult service which enables a conversation to occur about patient preferences**

## ***Progress in Disclosure of Adverse Events***

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- ❖ Progress in establishing systems and processes for disclosing adverse events to patients and families has lagged behind improvements in processes of care
- ❖ UIC is on the leading edge and is a national model
- ❖ AHRQ solicitation; link with patient safety and malpractice + House and Senate health care reform bills

## ***Why Disclosure of Adverse Events Matters***

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**Patient and family perspectives on patient safety and the aftermath of adverse events**

## ***The Wall of Silence***

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- ❖ Put a human face on medical error and describe patient/family and clinician experiences
- ❖ Describe patient and family wishes in the aftermath of error
- ❖ Highlight practical steps to advance patient safety

## ***Why Put a Human Face on Adverse Events?***

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- ❖ Make the invisible visible; we cannot fix a problem we cannot see or don't want to see
- ❖ Who are the 44,000 - 98,000 people who die from errors? = 500,000 - 1 million people a decade

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- ❖ Organizations that are more transparent about adverse outcomes are likely to make greater strides in quality and safety
  - ❖ This is the underpinning of AHRQ funding to advance the practice of disclosure
  - ❖ “If you can’t talk about it, you can’t fix it.”

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- ❖ Data persuade, emotion motivates

## Patient and Family Reflections on Disclosure

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- ❖ Interviews with patients/family members affected by adverse events:
  - Postal worker from New York
  - Journalist for NYT/Lehman Brothers analyst
  - Retired critical care nurse
  - New Jersey Vietnam veteran
- ❖ Ongoing dialogue with patients and families

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“If I can’t picture it, I can’t understand it.”

Albert Einstein

## ***Patient and Family Wishes in the Aftermath of Error***

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- ❖ Tell us the truth
- ❖ Don't abandon us
- ❖ Don't abandon clinicians involved in inadvertent error
- ❖ Their mantra: find the root cause and prevent it from happening again

## ***What Honesty/Disclosure Means to Patients***

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**Honesty: "It's like gold"**

Source: daughter of a man who died from error

## ***What Disclosure Means to Patients***

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*“What impressed me most was the way potentially adverse circumstances were handled. Shortly after surgery, I had a reaction to the anesthesia that required monitoring for several days. As soon as I regained consciousness I was apprised of the circumstances by a team of doctors...*

## ***What Disclosure Means to Patients***

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❖ *“... and nurses from cardiology, orthopedics, and pain management. Their honesty, openness and constant communication with me and each other put me at ease and gave me confidence in their skill and good judgment. How different from my earlier experience.”*

Source: Congressional testimony, Former Air Force Intelligence Officer

## ***Don't Abandon Us***

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*“I will never forget the way we were simply turned out into the street. The only call we ever got from the hospital was asking us if we would donate our son's eyes.”*

Source: Mother whose 15-year old son died from medical error

## ***Don't Abandon Us***

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*“My husband and a nurse supervisor clear his belongings out of the hospital room with his body lying on the bed. My husband and daughter drive back to the motel. I am not ready to leave my child and try to stay and sit in the hall, still clutching the clean pillow I had been planning to put on his bed that morning. The ward resumes its normal activity and I realize it is futile to stay. I am driven back to the motel in a police car by two security guards talking about paint.”*

## ***Don't Abandon Us***

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*“Hospitals should feel the need, as other industries do now, to fall all over themselves trying to make it up to the customer when something does go awry.”*

## ***Don't Abandon Each Other***

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*“I want to see physicians and nurses heal. The doctors missed the chance to hear my daughter say, “I forgive you.” There is so much richness in these words; but the doctors missed it...”*

Source: mother of a child paralyzed because of error

## ***Don't Abandon Each Other***

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*“I feel sorry for those doctors. You have to know they must feel bad about what happened. I know they didn't mean to do it.”*

*Source: 8 -year old girl paralyzed owing to a medical error*

## ***How Do You Care For Each Other?***

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- ❖ How we treat each other in the aftermath of an adverse outcome can have a profound effect...

## ***From This...***

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*“What did you do wrong?”*

## ***To This...***

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*“Where did we go wrong?”*

## ***Finding the Root Cause***

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- ❖ **Finding the root cause and making care safe**

*“I don’t want any other family to go through what we’ve had to go through. They need to find out what happened and why and fix what went wrong so it doesn’t happen to someone else. Maybe then my father’s death will have had a purpose.”*

Source: Daughter whose father died of medical error

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- ❖ **We can reclaim the moral and ethical responsibility that health care professionals have ceded to the lawyers.**

*“When we are honest with our patients, we can live divided no more.”*

### ***Imagine this...***

- ❖ The VA Hospital in Lexington, Kentucky has had a practice of disclosure
- ❖ Lawyers will not take a case against the hospital. Why?
- ❖ They knew they can't win – because the hospital would have done the right thing

## ***Disclosure Practices in Ancient Greek Medicine***

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***“In the dozens of accounts of errors in the ancient Greek texts, none advocates or illustrates telling the patient or a relative about the error.”***

Source: Steven Miles, *The Hippocratic Oath and the Ethics of Medicine*, Oxford University Press, 2003.

## ***Culture in Education and Training***

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***“When I was in medical school, we were taught that we would make mistakes and we would have to learn to bury them.”***

Source: Grandfather of 8-year old girl paralyzed as a consequence of a missed cancer diagnosis.

## ***The Futility of the Wall of Silence***

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**Burying medical mistakes is like burying radioactive waste.**

**You can never really bury them.**

**It will always be there, in the air, the water, the soil.**

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**“We begin to die the day we are silent about things that matter.”**

**Martin Luther King**

## ***Lessons from Other Professions***

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- ❖ Air Ontario jet crashed after takeoff in Canada in 1989
- ❖ Passengers alerted the flight attendant to snow on the wings
- ❖ Flight attendant said she did not question an area that in her mind was the pilots' responsibility

## ***Lessons from Other Professions***

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- ❖ A British Midlands 737 crashed in Leicestershire, England
- ❖ Safety board report: "Cabin crew became aware of ... flames emanating from the No. 1 engine, and this information was not communicated to the pilots."

**“If you see something unsafe, I expect you to speak up.”**

## ***CNO Leadership: Case of a patient missing in the hospital***

- ❖ **Elderly confused woman recently admitted to the hospital; family present in the unit**
- ❖ **Patient was missing during the night**
- ❖ **Nurse supervisor informed the CNO**

## ***Narrative from a CNO***

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*“... It was a Sunday morning and I was having breakfast with the night staff. It was Nurse Recognition Week. A new nurse supervisor came up to me and said that a patient had been missing during the night...”*

## ***Narrative from a CNO***

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*...The family was angry, blaming the hospital. I said, ‘Let’s go talk with the family.’ We walked to the patient’s room. The supervisor was a big guy and he was very shaken. I was frightened...”*

## ***Benevolent Gestures***

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*... I went into the room, sat down and introduced myself and said, 'I am so, so sorry. I came to apologize on behalf of the hospital.'*

*The daughter started crying and I held her hand. I realized the family was blaming themselves in part because they were there the whole time.*

## ***More Benevolent Gestures***

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*...I said, 'There is not going to be any blaming in this room.'*

*...After searching the hospital, we did find the patient...*

## ***More Benevolent Gestures***

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*... We had the patient thoroughly checked in the Emergency Department; they went over every inch of her whole body, and the family saw that we took great care in making sure their mother was alright. I stopped in to see the woman and her family every day...*

## ***Restoring Trust***

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*... The family thanked me for coming to see them -- they were stunned. We restored the family's trust in us.*

*I said to them, 'If you have lost faith in the unit where your mother went missing, we can move her to another unit.' The family did not want that – because their trust had been restored...*

## **Role Modeling for Nursing Staff**

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*... The nursing staff were in the room and standing in the hallway as I was talking to the family and holding the daughters' hands.*

*... They had never seen someone take ownership. I was stunned to hear the next day how many people knew about this. People came up to me in the halls and said, 'I heard about what happened and what you did...'*

## **Breaking the Cycle**

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*... I remember as a 25-year old nurse being publicly ridiculed for a mistake. There was a surgeon I trusted. The patient's hand was swelling after surgery. He said to cut the back of the dressing. I should have asked more questions. He screamed at me in the middle of the nursing station.*

## ***Breaking the Cycle***

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*... Now, years later in my role at the hospital, nothing punitive is going to happen if someone makes an unintentional mistake....*

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*“Drive out fear so that everyone may work effectively....”*

**Deming**

## ***Patient Safety and Clinical Ethics***

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3. How patient safety and clinical and organizational ethics go hand in hand

## ***Assumptions***

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- ❖ Patient safety is an ethical imperative
- ❖ Clinical and organizational ethics can and should inform, and be a driver of, patient safety

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- ❖ What can the field of ethics do to advance patient safety?
- ❖ What can individuals do?

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- ❖ In end-of-life care, individuals trained in ethics have been leaders in changing clinical practice, public policy (around advance directives), conducting public forums on end-of-life care.
- ❖ What can the field of ethics do to advance patient safety?