Why Are We Here? The Patient's Perspective

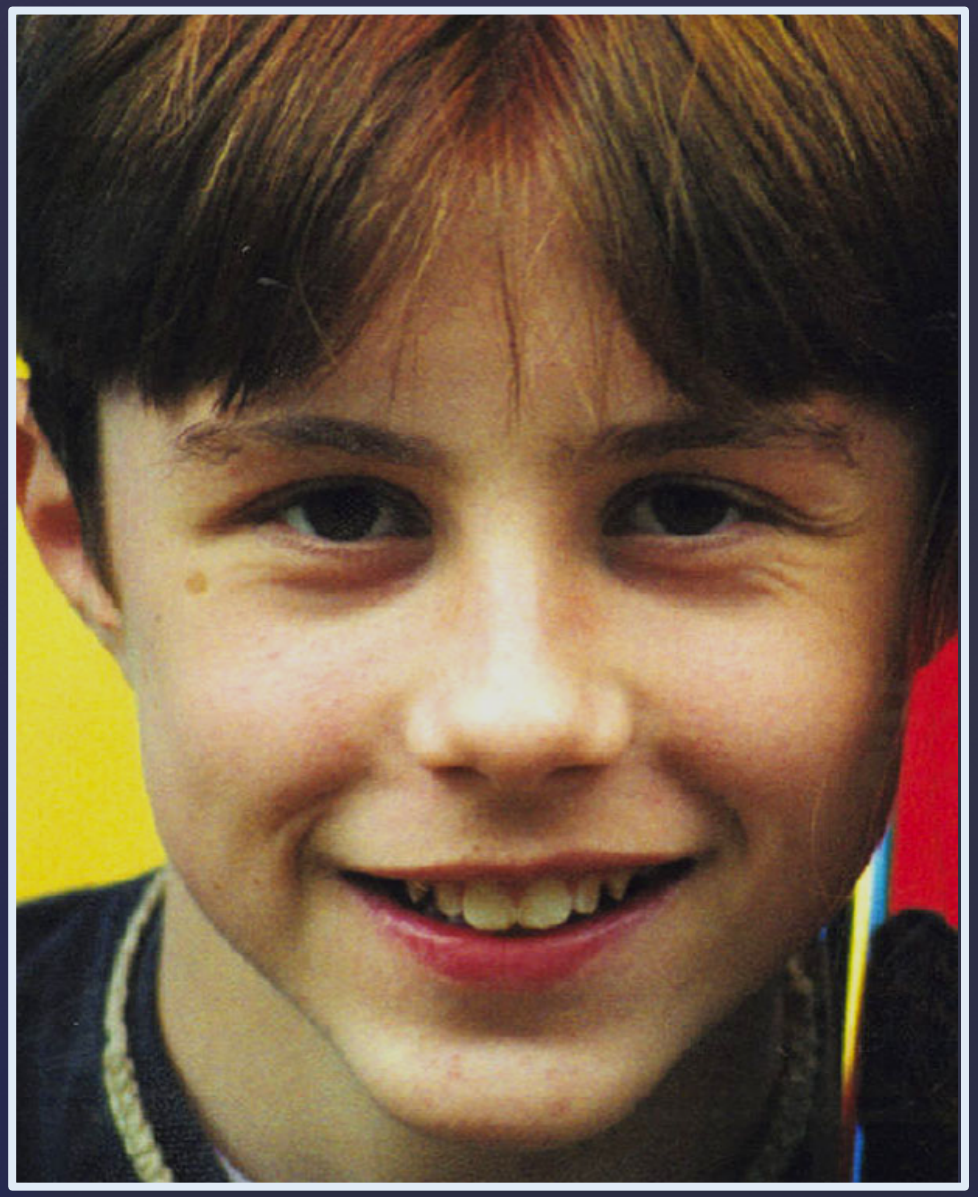
Helen Haskell
Mothers Against Medical Error
ISRRS Advisory Committee
Haskell.helen@gmail.com

No conflicts of interest to declare.

“...including a patient death”

The plural of anecdote is data.

-Raymond Wolfinger

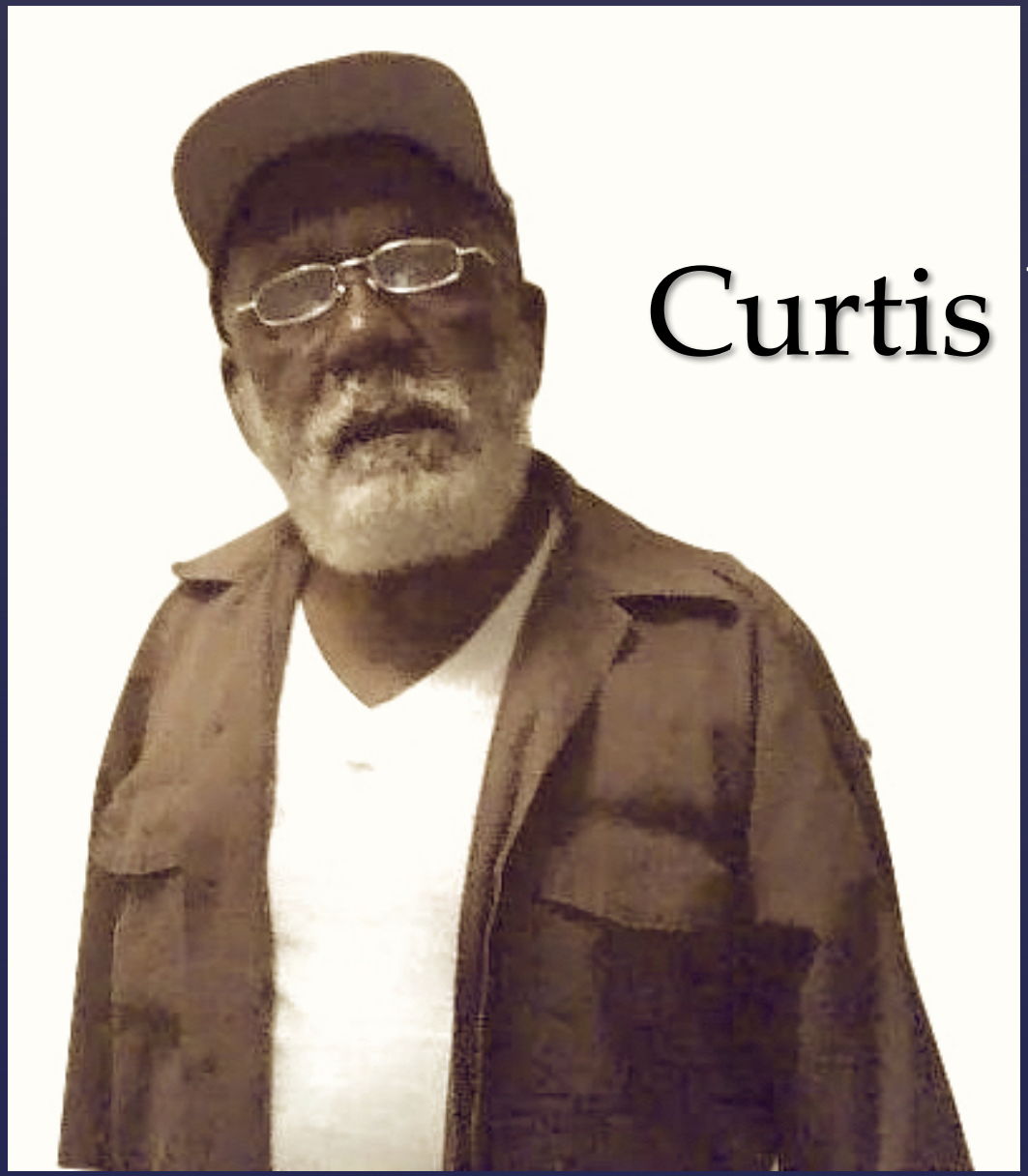


Lewis Blackman

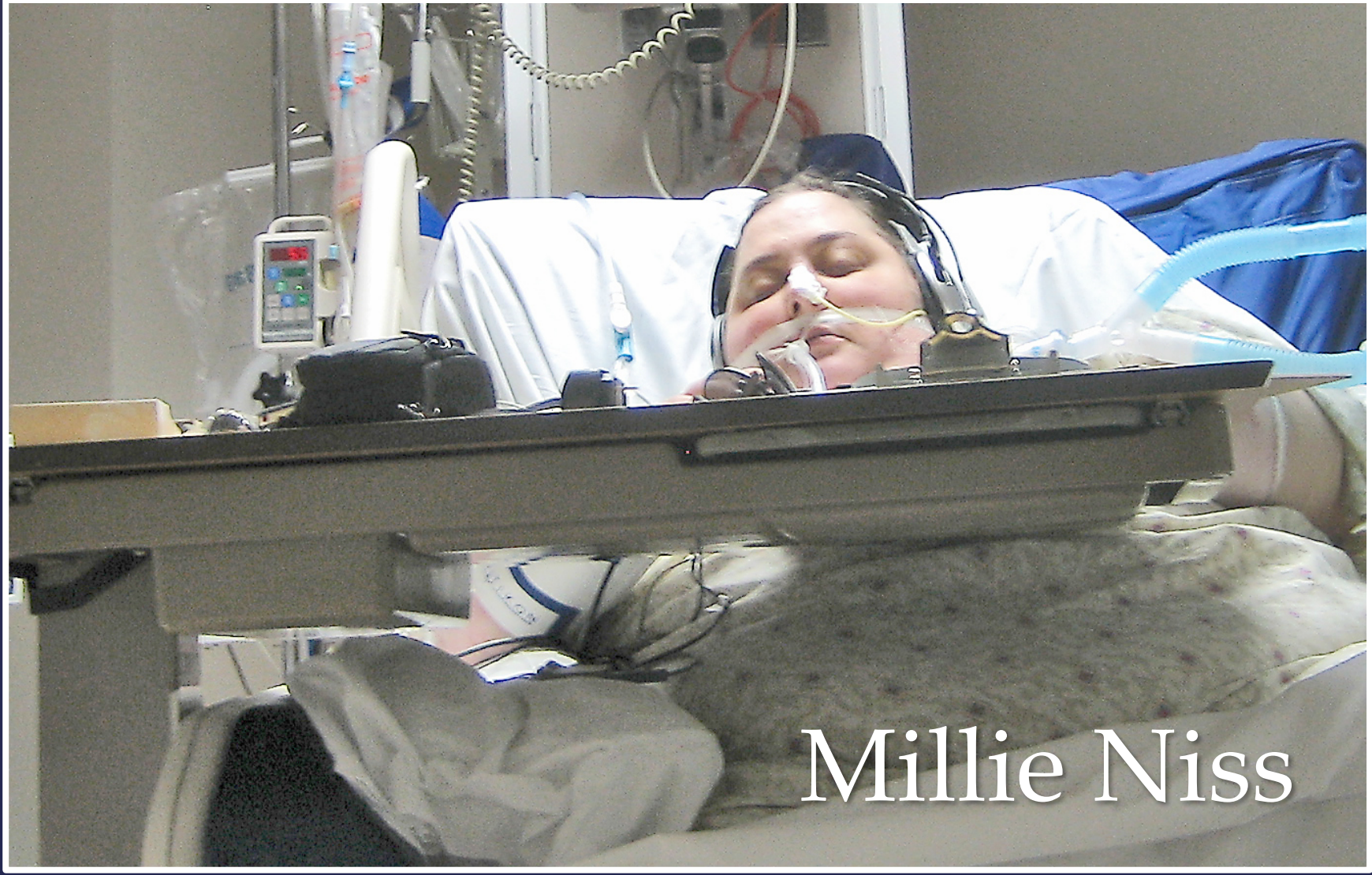
Josie King

Noah Lord

DJ Sterner



Curtis Bentley


Millie Niss

Patients' accounts of care

- Cross boundaries, as the patients do
- Focus on relationships, as the patients do
- Show the importance of professional, interpersonal and communication skills in clinical outcomes
- Reveal "the rest of the story"

Themes in patient stories

- Disempowerment
- Fear
- Bewilderment
- Shock
- Guilt

Relationships: Patient experiences of FTR

- False reassurances
- Bureaucratic thinking
- Groupthink
- Not listening
- Psychiatric labeling
- “Disruptive family”

Stereotyping

- Healthy child
- Anxious mother
- Minor procedure
- Routine monitoring
- Ethnic minority
- Terminal patient
- Overweight patient
- Elderly man

System factors as perceived by patients

- Overwork
- Knowledge deficits
- Fragmented care
- Lack of supervision/backup
- Fatigue

Patient factors

- Unfamiliarity with system
- Lack of knowledge
- Fatigue & isolation
- Fear of offending
- Desire not to bother busy HCWs
- No accessible authority to whom to appeal

The Patient Experience: Monitoring

- Lewis: pulse oximeter turned off
- Josie: no longer monitored
- DJ: unmonitored
- Curtis: no alarms

What can you learn from patients? The example of Lewis

I was the only one who:

- Recognized that my son was going into shock
- Really tried to understand what had happened
- Reported the incident to the drug manufacturer
- Proposed significant change

The Lewis Blackman Act

- All clinical hospital workers are identified by name, department, and status.
- Patients are provided written information about the role of trainees in the hospital.
- If asked, hospital staff must call a patient's attending physician or provide the physician's phone number to the patient.
- Hospitals provide a means through which patients can call directly for emergency medical assistance.

Condition H
(Condition Help)

The Josie King Call Line

A HELP line for Families

When to Call

1. If a noticeable medical change in the patient occurs and the health care team is not recognizing the concern.

2. If there is a breakdown in how care is being given and/or confusion over what needs to be done for the patient.

Ryan's Rule

Follow these steps to raise your concerns

Step 1
Talk to a nurse or doctor about your concerns.

If you are not satisfied with the response.

Step 2
Talk to the nurse in charge of the shift.

If you are not satisfied with the response.

Step 3
Phone 13 Health (13 43 25 84)
or ask a nurse and they will call on your behalf.
Request a Ryan's Rule Clinical Review and provide the following information:
- hospital name
- patient's name
- ward, bed number (of known)
- your contact number.

A Ryan's Rule nurse or doctor will review the patient and assist.

The Evolving Role of the Patient

- Patient-centered care
- Patient engagement
- Co-production

Emerging technology

- Continuous monitoring
- Patient-owned equipment
- Patient fitness monitoring devices
- Patient access to medical records

Moving toward partnership

- Ipad rounding
- Roving nurses
- Situational awareness
- Family-centered rounds
- Interactive bedside EHR

Capturing the patient experience

- Fragmentation blinds those working in it to the flaws of the system.
- Across the continuum of care, breakdowns often are visible only to the patient and family.

Patient reporting yields different results from doctor-reported outcomes

Basch E JNCI 2009, NEJM 2010

- Clinicians systematically downgrade symptoms compared with patients
- Patient adverse symptom reports correlate better with functional status than clinician reports do

…and also reveals errors and near misses not otherwise recorded.

Khan A et al JAMA Pediatrics 2016

- 21 parents reported 23 medical errors in a children's hospital; 10 (43%) were not documented in the medical record

Weissman J et al Annals Internal Medicine 2008

- Patients from 16 Boston hospitals reported 229 adverse events; 23% were not recorded in the medical record, including 12 of 32 (37.5%) serious, preventable in-hospital events

The Learning Institution…

- Analyzes rapid response call data
  - Especially patient-activated RRTs
- Practices open and honest response to adverse events
- Elicits patient reports
- Shadows patients to see through their eyes
- Involves patients in root cause analysis

Anyone who is involved in the problem should be involved in developing the solution.

-Chris Hart

National Transportation Safety Board

Putting the patient first—empowering patients to do everything they can for themselves and getting better results—is the best guarantee of a sustainable healthcare delivery system.

-Don Berwick