Starting from Scratch

Martha Deed, PhD

Health Watch USA Conference
Healthcare Transparency & Patient Advocacy
Lexington, Kentucky
November 1, 2013



In the beginning there was a patient who died.

Millie Niss, Poet, Web Artist, Daughter May 6, 1973 – November 29, 2009

She entered the hospital November 1, 2009.

Further Information on mother-daughter collaboration: http://www.poemeleon.org/martha-deed-on-collaboration/



A Vague H1N1 Epidemic

» Niagara County student dies of swine flu Undisclosed illness kills Buffalo student

By THOMAS J. PROHASKA AND AARON BESECKER - NEWS NIAGARA REPORTERS \cdot Published: November 19, 2009 at 12:00am

» Swine flu deaths in U.S. near 4,000 Niagara County records first fatality

By HENRY L. DAVIS - NEWS MEDICAL REPORTER · Published: November 13, 2009 at 12:00am

» Swine flu deaths tied to bacterial infections Finding alters view of experts

By HENRY L. DAVIS - NEWS MEDICAL REPORTER · Published: October 2, 2009 at 12:00am

» Swine flu vaccinations stir concern Pregnant women are among the reluctant

By MARY B. PASCIAK - NEWS STAFF REPORTER · Published: September 30, 2009 at 12:00am

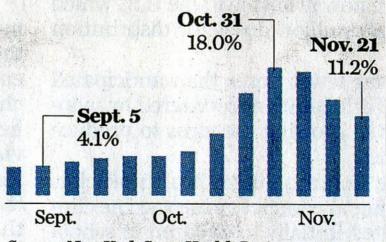


Source: The Buffalo News

Pandemic swine flu

Cases peak, but virus still causing illness

Percent of emergency room visits for flu-like illness in Buffalo/Rochester



Source: New York State Health Department

Source: The Buffalo News, 12/02/2009



Advocacy During Hospitalization

Subject: No bipap so far & it's pretty late

From: Millie Niss <men2@columbia.edu>

Reply-To: Millie Niss < men2@columbia.edu>

Date: 11/12/2009 12:35 AM

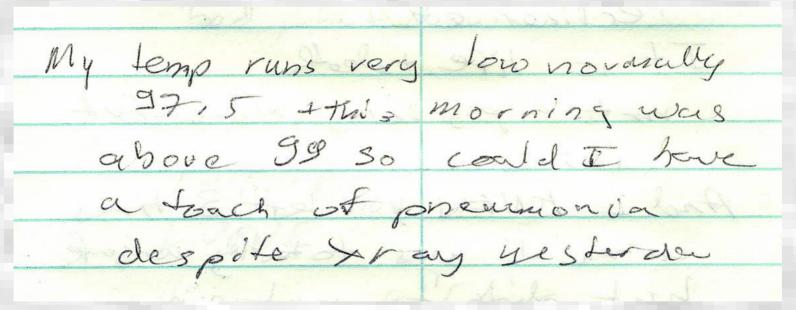
To: Martha L Deed

I am not complaining as the bipap scared me shitless....

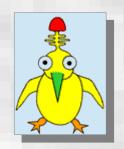
I am breathing much better on the mask & also after a treatment.



Advocacy During Hospitalization



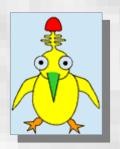
Source: Millie Niss, Hospital Notebook, 11/12/2009



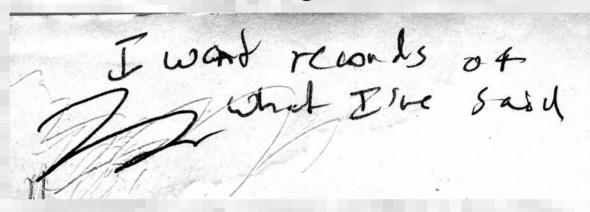
Advocacy During Hospitalization

I am still not confident that I will survive this (in the most literal sense of not dying) & [Mother's] advocacy has probably saved my life at least once last week. I don't think I am sick enough to die if the care were good, but there were life threatening errors. I have also gotten a lot of good care, but once you die or are terribly damaged it is too late to say "most of the care was ok."

Source: Millie Niss, Email to Father, cc to Mother, 11/15/2009 0939



Marching Orders



But now they are making dangerous medical mistakes and also being nasty and lying about me so as to discredit anything I say. Fortunately my mother has actually witnessed some of the events & we are media techies & have documented everything.

Source: Millie Niss, Hospital Notebook, 11/19/2009 & Email to Behcet's List, 11/16/2009



Advocacy During Hospitalization

1415 (ITY) 36 you & E BALLETS dt -> PICKWICKIEN ->
Wey for lown -> Muching Main / Maganetta BE

Catheter related BIT

Source: Medical Record, 11/28/2009 1415

He infection - She Staded infrançace The line was changed.



Source: Mother's Log, 11/28/2009

Pre-Death Advocacy

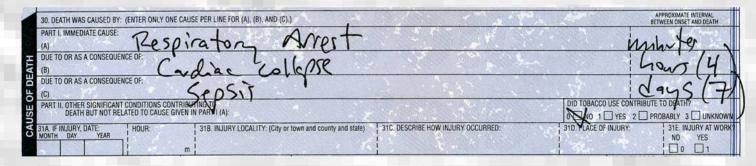
- •Public Health: Public not fully informed of H1N1 presence in the region
- •Patient and designated Family Advocate related concerns to front-line staff, supervisors, and administrators persistently and politely going up the ladder.
- •Patient's handoffs of advocacy issues to Mother misunderstood as "Mother is upsetting Patient."



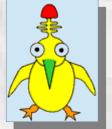


Next Steps:

- Order Autopsy
- Order full Hospital Record
- Obtain Death Certificate



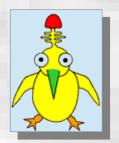




Healthcare Response

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Autopsy Findings

Cause of Death

Sepsis and vertebral osteomyelitis as one of several complications of long term immunosuppressive therapy to manage Behcet's disease. Multiple cultures from blood, urine, catheter antemortem as well as post mortem samples of lung noted to grow MRSA.

Report received Feb 12, 2010

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Autopsy Findings

Book problem jersa severe MASA infection + She have been dxof & sucreally remixed

Injection treatment not within any known Justocol-She ho leen on Vanco munin for at least a year with their level of infection

Rheumatologist's Explanation

Source: Mother's Log, 2/19/2010

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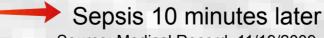


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	Physey BP 120/60 AR 115/mn 179 SAGL

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No infection



Source: Medical Record, 11/19/2009

Department of Health

Statement of Deficiencies issued June 7, 2010

Plan of correction approved on June 24, 2010

Regulatory Citations Deficiency Category

405.5 (b) (1) NURSING SERVICES.

Source: Hospital Profiles, NYS Department of Health, August 20, 2011

Conclusions:

The investigation determined that the patient did not utilize the BiPAP during the night on 1/11/09-1/12/09 despite an order. No documentation was found by Respiratory or Nursing that the patient refused the BiPAP. A deficiency will be cited under Nursing Services.

Investigation Report, August 5, 2010

Source: NYS Department of Health

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Know the Hospital's Culture

Confidential QA

Plan of Correction

NYSDOH Complaint #: 83170

Site:

MR#: 1001925168

S 351 405.5(b)(1) NURSING SERVICES.

Delivery of services. .

There was no documentation by Respiratory or Nursing regarding the application of the BiPAP overnight as ordered.

An interdisciplinary Plan of Correction inteeting was held on 06/15/10 with the Chief Nursing Officer, the Director for Cardio, Pulmonary and Imaging Services, the Nurse Manager for 2 SW and the Manager for QI and RA. It is well known that this patient was a very difficult patient and frequently refused to comply with the physician prescribed pulmonary treatments. However, the medical record is not well documented regarding the patient's refueblend this contributed to some of the issues identified by the NYSDOH in the Statement of Deficiencies. Management is well aware that if something is not documented, it did not happen. Therefore, staff documentation regarding this patient should have been more detailed and comprehensive.

Source: NYS Department of Health

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Identify Hospital Biases (if any)

again and required intubation. After the patient developed ascending paralysis and loss of sensation, Neurology was consulted. It was the opinion that the patient developed a transverse myelitis versus atypical Guillain-Barre versus spinal abscess. The patient was unable to have a CT or MRI to evaluate this possible lesion due to the patient's size. Neurology recommended the

CAT SCAN

Exam
CT Torso Study w+w/o contrast

Exam Date/Time 11/25/2009 3:26:38 PM Accession Number CT-09-0083181 Ordering Doctor

of the superficial soft tissues. Abnormal lucency within a thoracic segment felt most likely reflect T8. Finding was not clearly present on the study one year earlier. This raises the possibility of a neoplastic process. Abnormality in the setting of infection felt to be atypical. Correlation with bone scintigraphy may be helpful to maximally assess. The study is nondiagnostic to assess the spinal canal.

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Source: Top: NYS Department of Health, Case Summary, 4/8/ 2010, p.1 Bottom: CT Torso Study, 11/25/2009 (9 days post paralysis)



Consider Hospital Candor

Findings:

Interview on 5/5/10 at 10:20am with Infection Control Nurse revealed the ICU is not experiencing an increase in hospital acquired MRSA. . . . typically no more than 5 total cases of MRSA per month.

The patient involved in

this investigation had her urine tested upon arrival to ICU in November with a positive result for MRSA.

Source: Top: NYS Department of Health, Case Summary, 4/8/2010, pp 6, 7

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Consider Hospital Candor

BACTERIOLOGY

PROCEDURE: Urine Culture SOURCE: Cathoter Indwelling

BODY SITE: FREE TEXT SOURCE:

** FINAL REPORT ***

Final Report Verified:11/02/2009 18:34 Colony count 1,000 CFJ/ml Staphylococcus species

PROCEDURE: Blood Culture Routine (Aerobic)
SOURCE: Venipuncture
BODY SITE:
FREE TEXT SOURCE:

*** FINAL REPORT ***

Final Report Verified:11/08/2009 10:41 No bacteria or yeast isolated

Oct '09/ Dec '09 Jan '10/ Apr '10/ Mar '10 Aug '10 Source: Medical Record, 11/01/2009

COLLECTED: 11/01/2009 15:20

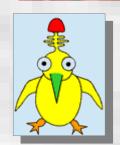
ACCESSION: 09-305-03775

STARTED: 11/01/2009 17:43

COLLECTED: 11/01/2009 15:30

ACCESSION: 09-305-03783

STARTED: 11/01/2009 18:16



Climbing a Stone Wall

- DOH permits 2nd complaint because of discrepancy between medical records and DOH staff interviews – 2nd complaint submitted Oct 31, 2010
- Hospital announces raised HAIs in 2009-10 are now down Jun 2011
 Source: The Buffalo News, June 20, 2011
- Citation issued for medication administered without a doctor's order 2nd complaint report received Nov 1, 2011
- DOH nurse apologizes for the meager results in debrief conference Nov 2011

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Tools - Government Studies

Adapted from Global Trigger Worksheet Source: Adverse Events in Hospitals OEI-06-08-00221, p 35

Oct '09/ Jan '10/ Apr '10/ Dec '09 Mar '10 Aug '10

Sep '10/Nov '11



	Cares Module Triggers	+	Event Description and Harm Category (E-I)
C1	Transfusion or use of blood products	A	X7
C2	Any code or arrest	4	X3
C3	Dialysis		
C4	Positive blood culture	A	3+
C5	X-ray or Doppler studies for emboli	A	3+
C6	Abrupt drop of greater than 25% in hemoglobin or hematocrit	A	Υ
C7	Patient fall		
C8	Pressure ukers		Υ
C9	Readmission within 30 days		Υ
C10	Restraint use		
CH	Healthcare-associated infection of any kind	A	Y
C12	In-hospital stroke		
C13	Transfer to higher level of care	4	Υ
CI4	Any procedure complication	A	Υ
C15	Other	4	Y No Bipap
	Intensive Care Module Triggers		
[1	Pneumonia onset	4	Y VAP, MRSA
12	Readmission to intensive care	A	Υ
13	In-unit procedure	4	Υ
14	Intubation/reintubation	A	Y

Tools - Connections

- Public Health Information to community Failed
- Family Advocacy in the hospital with staff and administrators Failed
- Obtain Medical record/Autopsy Treating Doctor Family Helpful
- Family research treatment/medical system issues Major step forward
- Family State Health Department Qualified Success
- Family Advocate Other Organized Advocates Major step forward Consumers Union Safe Patient Project Advocates Network (http://safepatientproject.org/)

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Apr '10/ Aug '10

Sep '10/Nov '11



Lethal Lag Time

Dr. Tom Ferguson via E-Patient Dave Bronkart http://epatientdave.com/2013/10/01/hey-watson-let-patients-help/

Carl Meyers

2nd Extended Family Member

July 20, 1938 – November 27, 2011

Same Hospital

Similar Problem

No MRI

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Sep '10/Nov '11





Martha Deed, PhD²⁴

Use What You Know

- Compile Case History & Writing The Last Collaboration, KevinMD etc.
- Obtain CMS Compliance Surveys Discover
 Hospital has no patient complaint policy or response plan
 MRSA contamination on computer keyboard in ICU
 (Accreditation agency issued Deficiencies and approved Plans of Correction
 I.e. you don't have to do everything.)
- Learn additional skills to enhance communication
 Clinical Problem Solving (UC San Francisco School of Medicine)
 Science of Patient Safety (Johns Hopkins)

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The Challenge – July 2013

Consumer Reports Hospital Ratings Released by State

- Everywhere we can we are trying to eliminate mistakes.
 WNY hospital in 3-way tie for 6th safest hospital in the State
- When there are incidents . . . we do research so it doesn't happen again. WNY hospital ranked above average in the State

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The Challenge – July 2012

Consumer Reports Hospital Ranked in the bottom quartile in NYS





Source: http://www.wivb.com/news/health/how-do-wny-hospitals-rank-in-new-list

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Sep '10/Nov '11



Moving Forward

- Build local coalitions between civilians and health care professionals
- Identify improvements in specific hospitals, e.g. notable websites: Strong Memorial publishes CMS surveys online (simplified, but acknowledging citations)
- · Identify barriers to care, e.g. access to imaging for obese patients
- · Examine staff organization and culture to make certain communication and action are efficient and complete, e.g. team consultations, checklists, time outs
- Strengthen connections among the branches: Admin & Bd of Directors Staff Patients, e.g. consider placing at-large patient member on key committees

Oct '09/ Dec '09

Jan '10/ Apr '10/ Mar '10

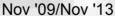
Aug '10

Sep '10/Nov '11



Further Reading

- •Adverse Events in Hospitals: National Incidence Among Medicare Beneficiaries. http://oig.hhs.gov/oei/reports/oei-06-09-00090.pdf
- •Adverse Events in Hospitals: Medicare's Response to Alleged Serious Events. http://oig.hhs.gov/oei/reports/oei-01-08-00590.pdf
- •Memorandum Report: Adverse Reports in Hospitals: Public Disclosure of Information about Events. http://oig.hhs.gov/oei/reports/oei-06-09-00360.pdf
- •Events in Hospitals: Methods for Identifying Events. http://oig.hhs.gov/oei/reports/oei-06-08-00221.pdf
- •John T. James, PhD. (2013). A New, Evidence-based Estimate of Patient Harms Associated with Hospital Care. Journal of Patient Safety.
- http://journals.lww.com/journalpatientsafety/Fulltext/2013/09000/A_New,_Evidence_based_Estimate_of_Patient Harms.2.aspx





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