MISPLACED CERTAINTY: THE HOBGOBLIN OF DIAGNOSTIC SAFETY / BY DAN BERG

PATIENT & FAMILY POSTER SERIES

INTRODUCTION:

Patient: 15-year old white female high school student; 5'3", 130 lbs.

BACKGROUND/PRESENTATION:

Presenting Symptoms: 1+ weeks fatigue, fever, sore throat, abdominal pain, jaundice.

Chronology of medical analysis and intervention:

- **Day 1:** Dramatic, hard-to-control nosebleed triggers urgent care visit. Presumptive Dx: UTI. Rx: Cephalexin.
- **Day 3:** Visit to pediatric clinic when symptoms don't improve. Rx changed to Cipro.
- **Day 5:** Visit to pediatric clinic for permission to travel. Lingering pain on right flank; sent to pediatric hospital for CT.

Radiology Differential Dx: "intrinsic gallbladder abnormalities such as cholecystitis and *diseases which can affect the gallbladder secondarily such as hepatitis." (italitcs added)*

HOSPITAL COURSE:

Patient admitted to pediatric hospital.

Admitting diagnosis: cholecystitis.

- **Day 6:** US; Radiology impression: Acute acalculous cholecystitis.
  - GI consult: "No need to search for alternative etiology."
- **Day 9:** HIDA; Radiology impression: Consistent with acute cholecystitis.
- **Day 10:** ERCP. Adult GI practice found no stone; performed endoscopic biliary sphincterotomy.
  - GI chart note: "Have we found unifying diagnosis?"
  - GI to parents: "Not sure your daughter should have surgery."
- **Day 11:** Patient goes to surgery, following consult between surgeon and pediatric GI: "...this most likely is the cause of patient's illness." Clean laparoscopic cholecystectomy; intraoperative liver biopsy. Nursing observation: jaundice and petechiae.

Post-surgery, patient is returned from PACU to non-surgical floor. PRBC, FFP, VIT K ordered but never arrived.

Patient dies 4 hours after surgery.

ULTIMATE DIAGNOSIS:

Autopsy cause of death: Complications of disseminated intravascular coagulation (DIC) and liver failure due to fulminant Epstein-Barr virus infection.

LAB VALUES:

Normal Range		Hospital Admission	Day 10 Pre-Surgery
0.2-1 mg/dL	Bili*	7	9.6
0.0- 0.3 mg/dL	Direct bili*	5.3	7.3
3.5- 4.9 g/dL	Alb*	2.5	2
42-168 U/L	Alk Phos*	431	659
30-65 U/L	ALT*	184	179
23-60 U/L	AST*	132	211
20-210 U/ L	Gamma GT*	290	ND
114-286 U/L	Lipase*	406	801
20-110 U/L	Amylase	85	102
12-16 g/dL	Hgb*	11.9	11.4
150-450 K/µL	Plts*	134	147
4.5-11.3 K/µL	WBC*	25	43.8
25-45%	% Lymphs*	86%	92%

*Outside Normal Range

SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

MISPLACED CERTAINTY: THE HOBGOBLIN OF DIAGNOSTIC SAFETY / DAN BERG

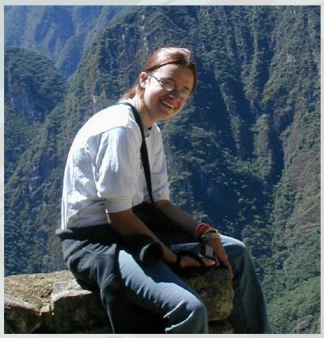
PATIENT & FAMILY POSTER SERIES

DISCUSSION:

- "The team attending the patient was experienced and well-qualified. But in this case, with its contraindications there was, perhaps, too much trust. Where was the empowered skeptic, or the culture that rewards those who question, question and question again? – DOUBT, Academic Pediatrics 2009;9:209–11

- There were multiple cognitive errors in the diagnosis and treatment of this patient. From the initial misdiagnosis—a UTI—one flawed observation led to another. Among the classic diagnostic errors, this case exhibits:
  - Premature closure/anchoring
  - Dx momentum
  - Overconfidence
  - Confirmation bias
  - Commission bias (compulsion to do something!)

- Care providers had: 1) a lack of curiosity—why were these labs so irregular and why hadn't someone else questioned them? 2) a misplaced certainty—following the admitting dx, acute cholecystitis was confirmed repeatedly as the correct diagnosis, disregarding clear indications of liver disease; and 3) a lack of effective communication between labs, radiology, and bedside providers, with no successful challenge to the assumptions that were ultimately, and fatally, wrong.



"How could we, Julia's parents, have prevented this outcome? We are haunted by this question. We can't undo what has been done; we can't bring Julia back. We believe the best we can do is share Julia's story and advocate for changes in the training, systems, and culture of medical care."

– Dan Berg and Welcome Jerde

OPPORTUNITIES TO IMPROVE:

- **Lead with curiosity:** For doctors, curiosity is fundamental to understanding each patient's unique experience of illness, building respectful relationships with patients and families, deepening self-awareness, supporting clinical reasoning, (and) avoiding premature closure.
- **Embrace uncertainty:** Providers can reduce everyone's discomfort by reframing uncertainty as a surmountable challenge, rather than as a threat. Expressing uncertainty can elicit additional history from the patient leading to a more accurate diagnosis.
- **Reassure honestly:** Rather than keeping the patient and family on the periphery of medical care planning, sharing the diagnostic process—co-producing the diagnosis with the patient/family—can be reassuring in a stressful time. Reassure them that there is a team—and who is leading it—that will do all they can to find the correct diagnosis and treatment plan.
- **Communicate effectively:** Effective communication is a two-way street. Information is transmitted by one party and received by another. But it must be understood, as well. It's the obligation of the medical provider to be clear and accurate, AND patient and insightful to ensure that the message is understood.

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SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

INTRODUCTION:

- Steven L. Coffee, II (patient) an African American male born September 28, 2012. Born 37 weeks and 6 days, weighing6 lbs, 1oz.

- Parents had no previous medical history of genetic or metabolic conditions. There were no documented extreme challenges during gestation.

BACKGROUND:

- Within the first 24 hours after birth and following a Phenylketonuria (PKU) test, the patient presented as jaundiced, with low glucose and high bilirubin levels, and displayed lethargic tendencies. The patient was held for 96 hours of observation and asked to return for a follow-up blood test.

- (Day 5 of life): The patient was discharged from a small military treatment facility hospital with instructions to sit in sunlight (natural phototherapy) to drive down high bilirubin levels. The patient was directed to return for additional blood tests.

- (Day 8 of life): Follow-up blood work confirmed high bilirubin levels despite artificial and natural phototherapy. The patient remained jaundiced despite phototherapy for elevated bilirubin levels and began showing signs of failure to thrive (declining birth weight) due to latching difficulty during nursing.

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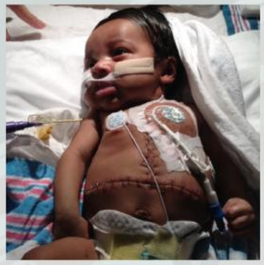


PRESENTATION:

- (Day 14 of life): Parents on speakerphone with provider told initial newborn screening possibly identified a single gene for galactosemia (S135L). Parents were directed to a larger military treatment facility but no prior calls happened between the different physicians.

- Larger facility relied on parents to relay diagnosis. Due to suspected GALT mutation (S135L), natural milk and formula were suspended and replaced with soy milk.

- (Day 16 of life): After a 48-hour observation, larger facility reintegrated natural milk and formula. Patient discharged from in-patient stay.

- Day 17 of life): The patient continued periodic episodes of emesis following feedings, continued lethargic behavior, and jaundiced appearance.

- Smaller military treatment facility verified GALT mutation and recommended parents suspend natural milk and formula.

- Smaller facility conceded the correct diagnosis due to the larger treatment facility conflicting discharge instructions for the patient.

COURSE OF CARE:

- (Day 55 of life) The patient visited ED following parent concern of swollen mass on upper leg. ED doctor only performed a visual exam and asserted the swollen mass on the leg was a swollen lymph node or fatty tissue.

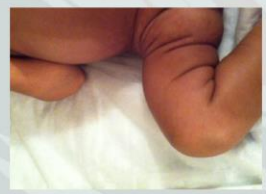
- (Day 56 of life) The patient returned to ED following additional genital swelling. ED doctor found no alarming findings during ultrasound of swollen areas. Discharged patient with instructions for a follow-up with a pediatrician in 48 hours.

ULTIMATE DIAGNOSIS:

- (Day 60 of life) Pediatrician performing physical exam noted abdominal distention and immediately referred patient to a larger military treatment center. A larger military treatment center put patient in a medically induced coma and transferred him to a private academic hospital in Washington, D.C.

- (Day 61 of life) A full genetic sequence was completed to reveal a negative mutated companion GALT gene Ser-192Arg and confirmed a diagnosis of galactosemia.

- (Day 68 of life) Patient underwent liver transplant due to fulminate liver failure secondary to galactosemia.



MILK DOESN'T DO THE BODY GOOD / Lt Col Steven L. Coffee, MA, EMCQSL PATIENT & FAMILY POSTER SERIES

DISCUSSION:

- Patient has a rare autosomal recessive metabolic disorder with an incidence between 1:16.000 and 1:60.000 in Europe and the USA [1]. Classic galactosemia (CG; OMIM: 230400) is caused by a deficiency of galactose-1-phosphate uridylyltransferase (GALT, EC 2.7.7.12). Due to this deficiency, newborns develop a life-threatening illness after the ingestion of breast milk or formula.

- There was both misdiagnosis and delayed diagnosis contributing to Steven's galactosemia.

- Initial signs of classic galactosemia include vomiting, yellowing of the skin (jaundice), low birth weight, poor nursing (latching on).

- Parents on multiple occasions inquired about why the patient continued having emesis following feeding. Parents were told to change the name brand of the formula, take more time during feeding, and use different types of dairy-based to aid in digestion.

- There are a few threads to pull in the tapestry; first is communication. There were physical and language barriers between the smaller hospital staff and the larger hospital staff.

- The pediatrician should have called ahead to the larger hospital to inform them of the potential diagnosis.

- There was lack of coordinated messaging and collaboration between treatment facilities on discharge instructions and follow-on care.

- The ED physician dismissed concerns by the parents and somewhat painted the parents as being overly sensitive new parents.

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TEACHING POINTS:

- Patients (and parents/caregivers) are partners in care.

- Regardless of the complexity in diagnosis, communication must remain at the most basic level to ensure comprehension and compliance.

- Bi-directional communication (between care teams and across internal/external treatment facilities) is essential to reducing harm.

- Trust parents when they believe something is not right—hear my voice.

- Following my son's experience, I partnered with the Society to Improve Diagnosis in Medicine (SIDM) as a speaker during the Diagnostic Error in Medicine (DEM) conference and inaugural Patients Improving Research in Diagnosis (PAIRED) project.

- I joined the patient's hospital Patient and Family Advisory Council for Quality and Safety (PFACQS) as a founding member and inaugural community chair. Through this PFACQS we refined and created hospital policies and procedures to bolster communication between patients and providers

- I co-founded Patients for Patient Safety United States, an organization committed to implementing the World Health Organization Global Patient Safety Action Plan.

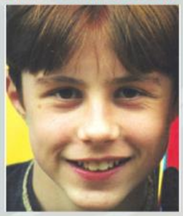
SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

LEWIS BLACKMAN: A CASE OF FAILURE TO RESCUE // HELEN HASKELL

PATIENT & FAMILY POSTER SERIES

INTRODUCTION:

- Lewis was a healthy, athletic 15-year-old, a soccer player, a saxophone player, a locally known child actor, and one of the top students in his state.



BACKGROUND:

- Lewis was born with a condition called pectus excavatum, in which the breastbone does not grow straight, giving the chest a sunken appearance. Lewis's case was mild and, as it is for most people, was primarily a cosmetic issue.

PRESENTATION:

- Lewis went into the hospital for a minimally invasive pectus repair on a Thursday. If there were any problems with his surgery, we were never told of them. For postoperative pain control, Lewis was given large doses of epidural hydrocodone and 6-hourly injections of the NSAID ketorolac. Problems with management of his IV fluids left him anuric for most of his stay.

- At 6:30 Sunday morning, half an hour after a ketorolac injection, Lewis was suddenly overwhelmed by an acute pain around his stomach, quite distinct from his surgical pain. We summoned the nurse urgently. When she arrived, Lewis described his pain as "5 out of 5."

COURSE OF CARE:

- The nurse was alarmed and ran from the room. A few minutes later she bustled back in and **announced that Lewis was simply constipated from the opioids he was taking. That casual comment, tossed out by some unknown person in the nurses' station, became his diagnosis.** It stuck with him for the next 30 hours, as his pulse and respiratory rate climbed, his temperature dropped, and his blood pressure rose too high, then fell too low. His belly swelled like a watermelon while urine flow again ceased.

- Our pleas for an experienced doctor were politely disregarded. By morning, Lewis had no detectable blood pressure. His 5/5 pain suddenly stopped, a turn of events we found alarming but that the residents who rounded reported back to their superiors as improvement. Several hours later Lewis went into cardiac arrest and died. No full physician had seen him for over 48 hours.

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ULTIMATE DIAGNOSIS:

- The cause of death was revealed by autopsy. Lewis had severe peritonitis, caused by a giant duodenal ulcer of a size and configuration usually associated with NSAID overdose. The ulcer had eroded into an underlying artery and he had lost nearly three fourths of his blood into his abdomen.

DISCUSSION:

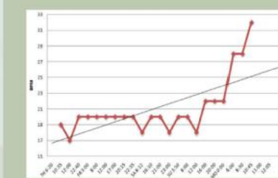
- NSAIDs, especially ketorolac, are notoriously associated with gastrointestinal ulcers. A **perforated ulcer** may not be the first thing to spring to mind in a healthy teenage boy, but whatever the cause, **it should have been obvious that Lewis was going into shock.** Apparently, no one saw that but me. Low weekend staffing and overreliance on inexperienced residents and nurses who felt constrained not to bother the physician on call were an invitation for **failure to rescue.**

TEACHING POINTS:

- In Lewis's case, as in many serious medical errors, there were many layers. His caregivers were not conversant with the potential side effects of the potent pain medications he was taking. Failure to recognize adverse drug events is a disturbingly common diagnostic mistake. Unfamiliarity with the signs of shock and sepsis, lack of goal-oriented teamwork, failure to listen to the patient and family and above all, failure even to consider a differential diagnosis were all significant factors in his death. But fundamentally, Lewis died from the effects of the hospital hierarchy. Had Lewis been well monitored and had experienced clinicians or a rapid response team readily available, he would be with us today.

- **Failure is to rescue is by definition diagnostic error.** It remains a leading cause of death in hospitals. Continuous monitoring, critical thinking, collaborative teamwork, and effective rapid response could change this picture dramatically.

LEWIS RESPIRATORY RATE:



LEWIS HEART RATE CHANGES:

SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

SAVED BY A SECOND SCAN / STACY HURT

PATIENT & FAMILY POSTER SERIES

INTRODUCTION:

- Patient was a 43-year-old mother to a child with special needs and head of training and development for a pharmaceutical company when she began to exhibit abdominal pain, blood in her stool, fatigue, constipation

BACKGROUND:

- Immediately upon reporting symptoms, the patients primary care provider referred her for a full work-up including a colonoscopy.
- The colonoscopy was conclusive for stage 2 colorectal cancer.
- The patient was sent for a diagnostic CT scan to explore the potential for liver metastasis due to size of the tumor and concern for spread, but the results indicated that the liver was clear.
- Upon urging from a childhood friend—a physician and stage 4 breast cancer survivor—the patient sought a second opinion at a National Cancer Institute-designated Cancer Center (UPMC Hillman)
- The oncologist at the NCI Cancer Center ordered a PET scan that revealed metastases to 27 areas including the rectum, liver, lungs, and lymph nodes. The cancer was upgraded from stage 2 to stage 4, and the treatment plan was significantly revised, from immediate surgery to adjuvant chemotherapy.

ULTIMATE DIAGNOSIS:

- Stage IV Metastatic Colorectal Cancer with Genetic Mutations MSS, BRAF wild, NRAS wild, KRAS mutant

DISCUSSION:

- This patient's self-advocacy and proximity to a National Cancer Institute-designated Cancer Center were pivotal aspects in her diagnostic journey, allowing for accurate detection of extensive metastases. Had her liver and other metastases been missed, it is likely she would not have survived.

- The prompt actions of the primary care physician and the patient herself were also key her ultimate successful outcome, which is currently at the 6-year mark of No Evidence of Disease. The colonoscopy was promptly ordered, scheduled, and completed, which allowed for the initial cancer diagnosis.

TEACHING POINTS:

- Clinicians should support and encourage patients to seek second opinions
- This patient was fortunate to receive care in an NCI-designated Cancer Center, but diagnostic quality should be held to the highest standards in all care settings, for all patients
- The patient's own research and self-advocacy contributed to her accurate diagnosis and to her successful treatment pathway. Patients should be supported and encourage to be their own best advocates.
- Symptoms should not be dismissed due to assumptions based on age or lack of family history

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SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

HYPERTROPHIC CARDIOMYOPATHY: A COMMON BUT OFTEN OVERLOOKED HEART CONDITION / Gwen Mayes, JD, MMSc

INTRODUCTION:

- My name is Gwen Mayes, a semi-retired health policy executive, lawyer, writer, and former physician assistant living in Annapolis, MD a few blocks from the Bay.

- I'm 65 years old and have lived with symptoms of hypertrophic cardiomyopathy (HCM) since a murmur was detected at birth. Although my mother mentioned that her father died of a sudden cardiac arrest at 49, the physician who delivered me dismissed it and said, "She's fine. Take her home and love her."

BACKGROUND:

- Symptoms of shortness of breath, dizziness, and fatigue followed me most of my childhood and teens, however, episodes that took me to the doctor were rare.

- Although my PCP in rural Kentucky, noted a murmur I was actively involved in climbing trees, canoeing, and being a cheerleader.

- In my late teens and twenties, as I began my own education as an intensive respiratory care physician assistant at Emory, I experienced syncope spells frequently working late at night.

- I was scared the same thing would happen to me that happened to my grandfather. I could feel the palpitations and racing heartbeat especially after working long hours on my feet or not being well hydrated. Because of my fears, however, I tried to ignore the symptoms as if nothing was wrong.

PRESENTATION:

- In 1988, at the age of 32, I had a severe syncope episode while riding the METRO in Washington, DC. Once in the ER, I was told I had had a heart attack and possibly a pulmonary embolism.

- At the time, I had normal oxygenation, but erratic heartbeats to the point it felt like a fish flopping in my chest. I was anxious and weak. Several medical students evaluated me; "Grade III murmur for sure" I heard them say.

- Later the following week, I was told I had not had a heart attack but rather most likely had IHSS (former name for HCM). The first thing the cardiologist said is "You will have a shortened life expectancy," a comment that defined decades of my life.

- I was advised not to have children, was told it was likely due to a genetic abnormality inherited from my mother (although she was asymptomatic), limited to moderate physical exercise, instructed to not get dehydrated, and told "do not push yourself" which was a meaningless comment to a young woman walking the halls of Congress.

COURSE OF CARE:

- Through the 90s my course of treatment included twice annual visits to the cardiologist, frequent Holter monitoring, frequent echocardiograms, and stress tests when I could tolerate them.

- There was no concept of patient advocacy or patient information; the cardiologist only had one other patient with HCM. There was limited research at NIH on septal myectomy.

- I was told "the emotional toll is likely to cause as much if not more harm than the physical limitations" and that has been true in many regards. I sought counseling, therapy, took antidepressants, and antianxiety meds.

- I was not a picture-perfect patient – I was a closet smoker, late night warrior, and involved in risky relationships with a "I don't care" attitude considering I had a "shortened life expectancy".

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SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

HYPERTROPHIC CARDIOMYOPATHY: A COMMON BUT OFTEN OVERLOOKED HEART CONDITION / Gwen Mayes, JD, MMSc

ULTIMATE DIAGNOSIS:

- The correct diagnosis was made in 1988 and I was placed on a beta-blocker and calcium channel blocker to steady my heart rhythm. However, on subsequent ER trips when palpitations were excessive or when I fainted in public, the medical staff were woefully unaware of HCM, its symptoms, and how it manifests.

- Despite care in large urban hospitals, and my own clinical education and former work as a PA in the cardiology field, there was a clear awkwardness or often – blank stare – when I tried to explain my condition and how to best treat me. One occasion, an ER nurse tried to cardio-shock me and had the paddles above my chest when I had to shove her away yelling "The T waves are double counting on the monitor" (explaining a HR of 178).

- I screamed, "Take my pulse at my carotid" and put my fingers on my neck. Her response, "I'd trust the monitor any day before what a patient told me." While arguing, the ER physician yelled from the nursing station that he'd just spoken with my cardiologist and to "back off" confirming what I had said to the nurse.

DISCUSSION:

- Hypertrophic Cardiomyopathy is now known to be the most common structural heart defect of genetic origin. It's most known as what causes sudden death in young athletes who "drop dead on the field." Statistics show a frequency of 1:500 and some posit 1:200. There are two types: obstructive (70% of the patients with HOCM) and non-obstructive. Many patients, especially older patients, have lived decades with misinformation and misdiagnoses including asthma, pulmonary hypertension, panic attacks, congestive heart failure, etc. There are approximately 40 centers of excellence and knowledge of the condition is increasing rapidly. The first-in-class drug is due to be approved by the FDA in early 2022.

- HCM has a strong genetic component, and it is often diagnosed among family members when one member has had an adverse event. Routine EKGs or even cardiac catheterization may not detect HCM. The gold standard is a echocardiogram with visualization of the hypertrophied left ventricular wall and surrounding impact to blood flow, ejection fraction, and valve function.

- Because of my clinical training, I can communicate aggressively, succinctly, and clearly to clinicians who are unfamiliar with HCM. The challenge for me is that episodes are sporadic and EMTs, ER staff are not familiar with the condition. Further, juggling medical records at three institutions on a ongoing basis is challenging.

TEACHING POINTS:

- Patients with chronic health conditions are frequently more knowledgeable of their condition, its quirks, and how it differs, than anyone in the room. Ask questions in reference to the noticeable changes to what is 'normal' for them.

- Just because you don't look "like a patient" doesn't mean something isn't wrong or doesn't need to be addressed.

- Many symptoms are universal to middle-aged menopausal women like fatigue, low sex drive, anxiety and but, the question is, how it compares to their more "normal" life.

- We are "more person than patient" and the amount of time we spend with clinicians is miniscule compared to the day-to-day rigors of living with illness. It affects our whole life.

- Don't forget to inquire about emotional and mental wellbeing.

- **Patients with chronic illnesses are educated and well versed on what is 'normal' for their body. Inquire as to trends, changes from that perspective, not what the clinician thinks 'should be normal."**

"I've spoken about women with heart disease on a national and local level to clinicians, civic leaders, legislators, and many others. The American Heart Association has included me on several podcasts and working groups to raise awareness of HCM. As a Patient Story Coach, healthcare industry companies hire me to work with cardiac patients to 'tell their story' in meaningful ways to improve standards of care, legislation, and practice guidelines, etc."

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SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

UNDER SURVEILLANCE BUT UNDER-SURVEILLED: A DELAYED DIAGNOSIS OF FALLOPIAN TUBE CANCER DESPITE SURVEILLANCE FOR TWO OTHER CANCERS AND REPORTING SYMPTOMS / LEIGH PATE

PATIENT & FAMILY POSTER SERIES

INTRODUCTION:

Patient is a 54-year-old female in Washington state, originally diagnosed in 2011 with stage 2B lobular breast cancer, and no recurrence at 5 years. She then developed advanced stage fallopian tube cancer but was not diagnosed for 4 months after first reporting symptoms, despite bi-yearly imaging and medical surveillance for breast cancer recurrence and proactive uterine cancer screening secondary to Tamoxifen use. She has since experienced three recurrences and/or residual or persistent disease. There are no germline BRCA or other known genetic mutations.

BACKGROUND:

- Following the lobular breast cancer diagnosis, patient started the anti-estrogen therapy Tamoxifen in 2012 and began having post-menopausal vaginal discharge in 2013 presumptively caused by a thickened uterine wall, a side effect of Tamoxifen.

- In 2013, she began annual surveillance for uterine cancer, a risk of Tamoxifen, with a gynecologist at the cancer center. The vaginal discharge stopped in 2015 but started again in 2016, along with abdominal pain and gastrointestinal symptoms.

ULTIMATE DIAGNOSIS:

- Stage 4B Fallopian Tube Cancer, High Grade Serous Epithelial Carcinoma

PRESENTATION:

- **August 2016:** Vaginal discharge started again after a year. Patient reported symptoms to both the breast oncology and gynecology offices at the cancer center. All assumed discharge was likely the Tamoxifen and told the patient to report for annual breast and uterine cancer surveillance in late November.

- **September 2016:** Increasing abdominal pain and discomfort and fatigue. Patient consulted the primary care doctor who prescribed probiotics and Miralax. Patient also reported symptoms to the gynecologist who did not feel an earlier appointment was necessary, as the symptoms were not those of uterine cancer.

- **Early October 2016:** Worsening upper right abdominal pain (under the ribs), primary care doctor advised patient to go to the emergency room. All blood tests including liver function were normal. An ultrasound of the abdomen ruled out gall bladder or appendix issues and cancer of the liver. A CT scan, triggered by a high D-Dimer ruled out a blood clot. Patient was sent home.

- **Mid October 2016:** Patient saw her primary care doctor for increasing GI distress and abdominal pain. They discussed the possibility that the lobular breast cancer metastasized to the GI tract and pelvis, and the doctor ordered an abdominal and pelvic MRI. Patient was prescribed an anti-spasmodic for suspected irritable bowel syndrome

- **Mid November 2016:** The MRI was done and showed enlarged ovaries.

- **End of November 2016:** At the patient's annual appointment with her gynecologist for uterine cancer surveillance, they reviewed the results of the MRI. The gynecologist ordered a trans-vaginal ultrasound, which showed enlarged ovaries with a blood supply. The gynecologist assured the patient this was likely benign fibroids, and that surgery would be needed to remove the ovaries. The gynecologist stated that he would be available to do the surgery in January.

- **End of November 2016:** Feeling unsettled about waiting until January, the patient reported the symptoms to her breast oncologist and requested the CA125 tumor marker test (common for ovarian cancer) along with the standard bloodwork for the annual breast surveillance appointment. The labs included all breast cancer tumor markers and CA125. The patient also requested a referral to a gynecologic oncologist for surgery to remove her ovaries.

The tumor markers showed that the CA125 level was 1545 (normal is <35). One breast tumor marker was also high. The breast oncologist ordered an emergency PET/CT Scan which showed cancer in both ovaries, in multiple lymph nodes and organs around the abdomen and pelvis, ascites (fluid) around the outside of the liver, and a tumor within the liver (likely the cause of the right side upper abdominal pain).

- **One Week Later:** Surgery was done to remove the ovaries and fallopian tubes and pathology confirmed a diagnosis of stage 4b fallopian tube cancer. Neo-adjuvant chemotherapy initiated within 3 weeks for first-line treatment.

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PATIENT & FAMILY POSTER SERIES

DISCUSSION:

Missed Diagnostic Opportunities

- The patient first reported symptoms in August but her providers declined to schedule an exam to evaluate the concerning symptoms, a 4-month diagnostic delay.

- When the patient was evaluated in the emergency room, appropriate scans and/or bloodwork could have identified the disease.

- The patient's history of lobular breast cancer--which can metastasize to the pelvis and gastrointestinal tract—should have raised alarm when she developed relevant symptoms.

Complicating and Contributing Factors

- Both the breast specialist and gynecologist monitored purely for symptoms of the surveilled cancer ("**tunnel vision**"). They (nor the primary care doctor) evaluated the full symptoms or considered the possibility of an additional type of cancer, or ordered a thorough work-up.

- Fallopian tube cancer, just like high grade serous ovarian cancer, is a rare and fast-growing cancer, and is often missed while more common diagnoses are ruled out. This hoofbeats concept, "when you hear hoofbeats look for horses, not zebras" can lead to zebras like fallopian tube/ovarian cancer being missed until they are advanced.

-Despite repeated contacts to the gynecologist office reporting symptoms and asking about an earlier surveillance appointment, **the provider dismissed and underplayed the potential seriousness of the patient's symptoms**, even suggesting the surgery to remove the enlarged ovaries be performed by someone not qualified to do gynecologic oncology procedures.

-A potential contributor to the delayed diagnosis was the transitions of care at the cancer center (the breast oncologist was leaving; the gynecologist had only seen the patient once before). **Patients are more vulnerable during care transitions.**

Despite ongoing treatment at a respected cancer center, this patient would likely have ended up in a catastrophic emergency without persistent self-advocacy and research. This points to **significant gaps in survivorship care and surveillance for cancer patients.** According to the National Cancer Institute, nearly one in five new cancer diagnoses happens in a person with a prior cancer diagnosis.

TEACHING POINTS:

- Listen to - and hear - your patient.

- Become familiar with symptoms of rare cancers like fallopian tube and ovarian cancer, and advocate for your patients with symptoms to be screened.

- Step back and try to evaluate all symptoms objectively to consider all potential diagnosis, instead of dismissing symptoms that don't fit a specific profile ("tunnel vision").

- Contribute to the creation of learning health systems that foster safer transitions in care so patient concerns and data are not lost.

- Consider survivorship care needs and risks for cancer survivors, and make sure those needs are integrated throughout their broader care team.

"My diagnosis was found through my own persistence and self-advocacy.

Had the first symptoms – vaginal discharge and soon after abdominal pain - been worked up with a trans-vaginal ultrasound and/or a CA125 blood test in August or September, it is possible this disease could have been diagnosed at an earlier stage when survival outcomes were better."

WHAT CAN YOU ENCOURAGE YOUR PATIENTS TO DO?

This patient and advocate is working to improve diagnostic quality by:

- Serving as a speaker for the Ovarian Cancer Research Alliance Survivor's Teaching Students program to educate medical students about symptoms of Ovarian Cancer

-Serving as a Consumer Reviewer for the Dept of Defense Ovarian Cancer Research Program

- Founding the Lobular Breast Cancer Alliance and serving as a Susan G. Komen Foundation Scholar.

REFERENCES:

A. Schattner, Teaching clinical medicine: the key principals, QJM: An International Journal of Medicine, Volume 108, Issue 6, June 2015, Pages 435–442, https://doi.org/10.1093/qjmed/hcv022, avoiding tunnel vision

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SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

THE MISSED WRIST / SUZ SCHRANDT

PATIENT & FAMILY POSTER SERIES

INTRODUCTION:

- 40 year-old white female, with a 25 year history of Juvenile Idiopathic Arthritis presenting for a total left wrist replacement. (4th joint replacement)
- Works in patient advocacy and health policy.

BACKGROUND:

- In 2015, patient had initial surgical consult and reported a complication of excessive post-surgical bleeding with all prior joint replacements, and asked that the procedure be done inpatient with surgical drains.
- Surgeon explained cauterization and other techniques had changed since her last surgery (in 2008) and that it would not be necessary to do the procedure inpatient or with any specific safeguards. She agreed to move forward.
- Surgery was completed outpatient; took twice as long as predicted but no noticeable complications, patient discharged home same-day.
- Within 12 hours patient began reporting unusual pain and significant swelling. She was seen in the office the following morning. At that visit, the surgeon forcibly cut off the "soft" casting that had become hardened from the amount of bleeding from the site. Patient was sent home and told the swelling and pain were normal.
- For the next 36 hours patient continued to report pain, discoloration, swelling, and finally numbness and paralysis.
- At 48 hours post-op patient unwrapped bandage and found multiple blisters around the wound; surgeon requested she report to the ER to be admitted.

PRESENTATION:

- Patient presented to ER with grossly swollen bluish hand, cold to the touch, numb, and non-responsive to stimuli. Patient was admitted, and Morphine and steroids administered while course of action was determined.

COURSE OF CARE:

- Provisional diagnosis was compartment syndrome-like event due to excessive post-surgical bleeding.
- A fasciotomy was contemplated but there was concern it would lead to another bleeding event; patient remained NPO for first four days as surgery continued to be discussed.
- Treatment was high-dose steroids and elevation, with the affected hand hoisted to an IV pole.
- Patient discharged on the fifth day when swelling had begun to subside and mild sensation was beginning to come back. Instructed to continue "elevation" protocol at home.
- Patient required multiple weeks of rehabilitation for nerve damage caused by the event, before normal wrist arthroplasty rehabilitation could begin.
- Elevation protocol exacerbated the inflammation and arthritis in patient's left shoulder and elbow.

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SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

THE MISSED WRIST / SUZ SCHRANDT

PATIENT & FAMILY POSTER SERIES

DISCUSSION:

- Despite the patient's own recounting of prior surgical bleeding episodes, her requests to have the surgery inpatient with a surgical drain were declined.
- On the second day of the hospitalization, the surgeon apologized, saying "you told me this was going to happen and I should have listened to you, and I'm sorry". There was no further action by the hospital or the surgeon related to the errors, beyond the general management of the clinical situation.
- The mild nerve damage that resulted from the event was fairly minor, but had the patient and her husband not been vocal and persistent in their advocacy, the outcomes could have been far worse. The original guidance was to be seen two weeks from the date of surgery. As with so many issues in diagnostic quality and safety, this raises questions about what may have happened to a patient who was less resourced, and felt less empowered to speak up for herself.

ULTIMATE DIAGNOSIS:

Compartment syndrome-like event, unexplained excessive post-surgical bleeding.

"For a long time, I was embarrassed to talk about what happened because I am such a long-tenured patient and have worked in health policy and patient engagement for more than two decades. How could something like this happen to me?! But ultimately I decided that is why I needed to be vocal. My outcomes could have been so much worse. What might have happened to someone who did not speak up and waited for the two-week mark to be seen?"

- Suz Schrandt

WHAT CAN WE LEARN?

-Listening to patients is paramount; this patient accurately reported multiple prior instances of excessive bleeding with a proposed approach to prevent harm but the information was disregarded. Clinical training should include methods and capacity building for best integrating patient and family- provided information.

- Assessment of invisible symptoms like pain is a critical skill; the surgeon only took action after an objective finding (blisters) appeared.

- To the patient's knowledge, there was no official action taken on the part of the hospital who may not even be aware of the event, so no learning or process improvement could be generated from her case. Hospitals and healthcare organizations need systematic methods for capturing and responding to diagnostic errors. In this case, the patient and her health plan paid for all the additional care.

- The patient's lack of a complete and accurate medical record inhibited her ability to effectively communicate with the surgeon. No information about the prior bleeding events—or the steps taken to respond—were included in her records, despite requests to each of the hospitals for all records from each episode of care. Perhaps if the patient would have had clinical documentation of these issues, she would have been taken more seriously.

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SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

KOTI BATEMAN EPPERSON

PATIENT & FAMILY POSTER SERIES

INTRODUCTION:

- 6-year-old white male.
- Suffers with Celiac disease but has no other underlying health conditions or issues.

BACKGROUND:

- Patient was asymptomatic until the day of the medical emergency.

- His Kindergarten year had been uneventful regarding illnesses and other maladies; the most worrisome was an occasional head cold, or sinus infection.

- The day of the medical emergency, the male patient played a soccer game and celebrated an older sibling's birthday that afternoon. It was only then that he began to complain of not feeling well. He had spiked a fever and was complaining of stomach upset. That stomach pain continued to increase throughout the day, as did the fever. His breathing became more labored, and he was very restless.

PRESENTATION:

- Our first arrival at the point of care was to a local ED. There they did a blood and metabolic panel, a chest x-ray, and a urinalysis. Vitals were a temperature of 101, pulse ox at 93 with respirations at 30 a minute. Pulse was in the 130's. Patient was sent home from the ED visit with a diagnosis of a "nasty virus" that just needed to run its course. We did not find out until much later that the hospitalist and nurses on duty that evening did not read patient's lab work until 20 minutes AFTER discharge, and even then, did not call the family. The lab work clearly indicated patient was in distress.

- Approximately 6 hours later, patient was transported to the nearest children's hospital by family. The thought at that time was that appendicitis was a strong possibility due to the extreme abdominal pain. In the ED, he was subjected to another round of blood work, a chest x-ray (which was at the request of the family since he had already had a chest x-ray just hours before at the previous hospital) and an ultrasound of his abdomen. At this point, patient was not consistently lucid, vomiting and in tremendous pain. While waiting for the results of the second chest x-ray, patient stopped breathing due to acute pulmonary edema. He was taken to Trauma where many life saving measure were taken to try and stabilize him. It was there that he was diagnosed with septic shock. He was eventually intubated, taken for a CT scan and admitted to the PICU.

COURSE OF CARE:

- Patient was admitted to the children's hospital for a total of 14 days. He was sedated and intubated for 7 of those days. He was given, Fentanyl, Propofol, and Chloral Hydrate during the sedation period. He was on vasopressor therapy, Ampicillin and Tetracycline. He was given Lasix to reduce the tremendous amount of fluid in his little body. He had epinephrine on board "just in case". He had a central line, an arterial line, and a nasogastric tube. Chest x-rays were performed twice a day and another 2 ultra-sounds were performed due to the development of an intussusception due to trauma. Miraculously this resolved itself and surgery was not necessary to repair. Once intubation was no longer necessary and due to withdrawal symptoms, patient was given a 5-day course of Methadone and Ativan. Upon discharge, patient was sent home with a 30-day prescription of Amoxicillin and Senna as well as an incentive spirometer for a very persistent pleural effusion. He weighed only 38 pounds.

- While the children's hospital was wonderful and undoubtedly saved the patient's life, we were sent home with absolutely zero information on what to expect moving forward after septic shock. We had no concept of Post-Sepsis Syndrome and all the difficulties that it would cause for him over the next 2 years. There was no discussion on the dangers of recurrent sepsis and the overwhelming chance that it could happen again within the first year after survival.

REFERENCES:

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SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

KOTI BATEMAN EPPERSON

PATIENT & FAMILY POSTER SERIES

ULTIMATE DIAGNOSIS:

- Correct diagnosis was septic shock due to the group A strep virus in the bloodstream. The team of doctors at the large children's hospital within driving range to us identified the cause of the septic shock.

- Patient suffered night-terrors, joint pain, difficulty with gross motor skills, failure to control bladder, and PTSD. While the majority of these issues have subsided or completely gone away, they were all avoidable with a correct diagnosis.

DISCUSSION:

According to Sepsis Alliance, a patient advocacy organization dedicated to patients and families affected by sepsis:

- Sepsis is the number 1 cost of hospitalization in the U.S. Costs for acute sepsis hospitalization and skilled nursing are estimated to be $62 billion annually. This is only a portion of all sepsis-related costs since there are substantial additional costs after discharge for many.

- The average cost per hospital stay for sepsis is double the average cost per stay across all other conditions. And, sepsis is the primary cause of readmission to the hospital, costing more than $3.5 billion each year.

- Studies investigating survival have reported slightly different numbers, but it appears that on average, approximately 30% of patients diagnosed with severe sepsis do not survive. Up to 50% of survivors suffer from post-sepsis syndrome. Until a cure for sepsis is found, early detection and treatment is essential for survival and limiting disability for survivors.

- Post-sepsis syndrome (PSS) is a condition that affects up to 50% of sepsis survivors. It includes physical and/or psychological long-term effects. Children can also live with lasting issues related to sepsis. About 34% of pediatric sepsis survivors are not back to pre-sepsis functioning for at least 28 days after their hospitalization. The numbers could be higher as another study that included teachers who evaluated students who had had sepsis. The researchers found that 44% of the children who had been in septic shock had cognitive difficulties compared with healthy children. They are also more likely to have PTSD if they were treated in a pediatric ICU

TEACHING POINTS:

- We trusted the hospital staff at the first hospital with the care of our son. Ultimately, we believe their failure to diagnose was the root cause of the numerous traumatic interventions to follow. Even now, it is difficult to ever feel safe again. Every little thing that happens causes more anxiety and questions than prior to our experience with septic shock.

- Clearly one thing to be learned is to never release a patient before labs come back, even if you believe you already have a diagnosis. Had we not followed our gut feeling that something was very wrong that night, if we had just gone home and given our son "more Tylenol" and "waited it out" as the first ED physician had suggested, our son would no longer be with us. We are so fortunate to live within an hour of one of the best children's hospitals in the nation or I do not believe our son would have survived.

- Our son's survival has led our family to a commitment of advocacy for survivors of sepsis and families who have lost a loved one to sepsis. We are active members of Sepsis Alliance, as well as the Patient Engagement Committee through SIDM. We are currently seeking solutions with our State lawmakers to hold hospitals and physicians accountable for missed diagnosis that results in traumatic interventions, not just mortality.

REFERENCES:

"Sepsis Alliance, www.sepsis.org", and then add these three cites:
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