



The Best Care, The Lowest Cost: One Idea at a Time



CONTENTS

INTRODUCTION	3
2015 NATIONAL STORY CONTEST	4
MORE FROM THE FRONT LINES	12
JUDGES	20
PARTNERS	21

INTRODUCTION

“While both clinicians and hospital administrators want to and need to address waste and bend the cost curve, it is a daily struggle to keep healthcare costs down while trying to deliver high quality care. While progress is being made, the challenge is that those ideas and experiences aren’t being shared. It’s time to change that.”

~Tom Balcezak, MD, MPH, Chief Medical Officer at Yale-New Haven Hospital

The Best Care, The Lowest Cost: One Idea at a Time is a national story contest that invited patients, clinicians and administrators to share real stories of successes and failures in pursuit of affordable healthcare. According to a New York Times/CBS Poll, half of Americans have identified the affordability of basic medical care as a hardship. With healthcare costs projected to exceed \$5 trillion annually within the next 10 years, now is the time to bring clinical and financial leaders together to make care affordable.

This National Story Contest provided an opportunity to “open source” ideas to start a conversation between physicians and finance leaders on how to create a healthcare system that truly delivers value. To provide a broader platform for those stories to be shared, four organizations representing the clinical, financial and technology realms of healthcare—Costs of Care, Healthcare Financial Management Association, Yale New Haven Health System and Strata Decision Technology—came together to launch this initiative.

Stakeholders shared experiences and ideas to reduce cost and improve care. Those stories are shared in this

e-book—stories like “Doc, I Need an MRI,” which outlines a simple solution of embedding a primary care office into a low-income housing building to illustrate how delivering care to patients where they live prevents unnecessary emergency department visits. “Two Sides” tells of integrating medical, behavioral and social interventions at one care site, thereby providing more comprehensive care at a lower cost. And “The Cost of Not Caring” shares the story of Lydia, whose complex and costly end-of-life care might have been delivered more effectively through simple at-home interventions.

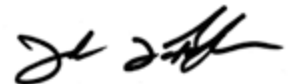
This e-book includes stories from both this contest and prior Costs of Care contests over the last five years with the hope to inspire others to question their assumptions about the way healthcare is delivered, think creatively about solutions, and ultimately help shape the transformation of our healthcare system to deliver higher value care.

As you embark on this important work, we would love to hear your stories as well. Please send them to info@costsofcare.org - we will continue to post the best stories we receive each week on the CostsOfCare.org website.


So, enjoy the e-book and be sure to add to the conversation. It’s a great opportunity to drive better value in healthcare and to make a difference in the communities we serve.



Dan Michelson
Strata Decision Technology



Joseph J. Fifer
Healthcare Financial
Management Association



Steve Allegretto
Yale New Haven Health System



Neel Shah, MD, MPP
Costs of Care

2015 NATIONAL STORY CONTEST

'DOC, I NEED AN MRI'	5
TWO SIDES	6
THE COST OF NOT CARING	7
LOCATION, LOCATION, LOCATION: A BABY STEP TO REDUCING THE HARDSHIP OF HEALTH CARE DELIVERY	8
DISCHARGE IS NOT A DEAD END: PATIENT NAVIGATORS IN THE ED	9
EDUCATED HEALTHCARE CONSUMERS? HAPPIER ENDINGS FOR URGENT CARE.	10
A PATIENT-CENTERED APPROACH TO IMPROVING QUALITY AND DECREASING COST OF CARE	11

‘Doc, I Need an MRI’

By Patricia Czapp, M.D.

“Doc I need an MRI for my back.” I recognized the voice immediately and turned to greet one of my favorite patients, Mr. P. There he was, smiling, leaning on his walker.

Mr. P. visits me several times a day in my primary care office, which is essentially in his living room. The practice itself, fewer than 1,000 square feet, is on the first floor of a high-rise apartment building that houses disabled and low-income adults.

My team and I provide primary care to the residents of the building (a public housing unit) and the surrounding community, a diverse population whose common characteristics are social isolation, low health literacy and low general literacy, high prevalence of behavioral health problems, and limited transportation.

We came to practice in the building because our health system, Anne Arundel Medical Center, noted several years ago that there was a high number of emergency department (ED) visits from individuals from one address. We visited the address to meet the residents of the building and their landlord, the local housing authority.

We found a population of individuals who were aged beyond their years and suffering from preventable complications of chronic disease—individuals like Mr. P., for whom a visit to the hospital meets medical and nonmedical needs.

Mr. P. is a man living a marginalized existence. He thrives when people take the time to listen to him, touch him, and show him that they care. For many decades, he found this comfort in the ED. When his landlord agreed to try an experiment with us, we came to practice in his building.

Mr. P. was one of our earliest patients.

We provided him with a low-cost alternative to meet his needs and to do so with kindness, tolerance, and generosity.

“What happened to your back, Mr. P.?” I asked. “Did you fall or hurt yourself?”

“No, doctor,” he said. “I just woke up, got out of bed, and it hurt real bad for a while. I could hardly stand up.”

Rather than lecture him about the lack of medical necessity for an MRI scan, I accompanied him to his modest apartment where we reviewed the condition of his bed and mattress and suggested alternative ways to use pillows to support his back. Mr. P. beamed, “Thank you so much.” And then he shuffled toward the Community Room.

If we had not been there to intercept Mr. P., he would have dialed 911. It shocks many to learn that individuals use the ED for nonmedical needs. But for some, this is the only way they feel human.

Our practice has been open for two years. In that time, we have experienced a significant decrease in medical 911 calls, ED visits, admissions, and readmissions of residents of the apartment building. They have an alternative to the ED now, and we meet their social needs in their living room, one visit at a time, sometimes multiple times a day ...

“Doc, I need a CT scan for my head.”

Two Sides

By Laura Sander

“The blue side is what I display to people, and the dark side is just that. The thoughts that race in my head are in yellow and white. Red is anger. My mouth is dark on one side because I say things I shouldn’t ...”

This patient—let’s call her “Sue”—is best able to express her emotions through art therapy. Sue is a 24-year-old mother and trauma survivor, and she has been sick as long as she can remember. When we met in late 2014, she had an undiagnosed autoimmune condition and had not been in psychiatric care since age 18. She had limited access to food, was having difficulty paying her rent, and was on the verge of being evicted. Sue was in need of intense attention to all aspects of her health: medical, behavioral, and social.

We are Priority Access Primary Care (PAPC), a primary care team dedicated to high-cost, high-need Medicaid patients. Through a unique partnership between Johns Hopkins Community Physicians and Johns Hopkins HealthCare’s Priority Partners Managed Care Organization, we identify patients based on disproportionate total costs and the number of emergency department (ED) visits and hospitalizations.

Sue was a good candidate for our program: In the previous six months, she visited the ED 27 times and had two admissions. Her healthcare costs reflected this high utilization: \$82,000 in six months, more than seven times what is expected for her age and health conditions. Her costs were disproportionate because the majority of her care was inappropriately delivered in the ED and hospital.

PAPC emphasizes primary care to combat high ED and hospital costs. Our patients encounter 45-minute visits with a focus on care coordination, integrated behavioral health services via an

embedded clinical social worker, and integrated social services via a community health worker. Sue was connected to specialists, diagnosed, and started on treatment for Crohn’s disease. She also was diagnosed with bipolar disorder and engaged in group and art therapy, and she has been connected with multiple social services.

Like all of our patients, Sue has 24/7 direct cell phone access to a provider for urgent needs, and we are notified immediately when she presents to an ED. We assist with care transitions and provide home visits for acute or chronic needs. This focus on primary care has helped Sue avoid hospitalizations and reduce her ER visits by two-thirds, to nine, in the past six months. Her costs have decreased by more than half—to \$37,000.

Representing two sides of our health system—care delivery and payment—PAPC has aligned its financial goals with our mission to serve the most vulnerable Baltimoreans. As such, we deliver appropriate, high-quality care at a reduced cost. We have more than 50 patients who, like Sue, have complex health needs and require extension of traditional biomedical models. In less than one year, by investing in and intensely caring for our sickest and costliest patients, we have achieved a 20 percent return on investment. We have learned much from others engaged in similar work and are continually evaluating, improving, and sharing our findings. Benefits start with the individual and extend to the health system, affecting both sides of our health system and all aspects of our patients’ lives.

The Cost of Not Caring

By Stephen Miranda

By the time Lydia came to Pathways Hospice, she had suffered from several hospitalizations. I was her “companionship volunteer.” During my training, I learned about the power of a volunteer visit, but I had my doubts. At 19, I hardly had the life experience, let alone the medical knowledge, to make a difference in her care—or so I thought. It turns out I had underestimated the power of human contact. After only a few months of working with her, Lydia was becoming more energetic and we struck up a vibrant friendship. It seemed that my visits provided the mental stimulation she longed for at her nursing home, and every day she appeared to be getting better. Paradoxically, however, it was this improvement that ultimately took her life.

Lydia was discharged from hospice. Her physician was no longer able to certify that she had less than six months to live. She was no longer eligible for hospice services, and I was no longer permitted to visit with her. That was the hardest part: I knew how much my visits meant to Lydia. Many weekdays, I answered her worried phone calls, reassuring her I would be there on Saturday. How would she fare on her own, without family or friends to visit her? A few months later, I had my answer. My volunteer coordinator called to inform me that Lydia was being readmitted to hospice. Her disease was worsening, but considering the progress she made while in hospice, it was hard to believe that her newfound isolation wasn’t playing a role.

We define the value of care as the quality of that care in relation to its cost. But how do we measure the value of the care we don’t provide? Lydia died a few weeks after her readmission, and I was the last person she spoke to. I still wonder how the end of her life would have been different had she never been discharged from hospice. All Lydia needed was someone to check in on her. Who knows how many hospitalizations a friendship could have

prevented—not to mention the money that it would have saved the healthcare system. In 2009, Medicare spent \$55 billion on hospital bills during the last two months of life, with daily charges exceeding \$6,200. In comparison, Medicare spent \$13 billion on hospice in 2010—\$153 daily per person.

Of all the healthcare dollars spent on Lydia, could we have found a way to get her the help she really needed at home to prevent her arduous hospitalizations? Instead, Lydia painfully made her way through a maze of providers to a skilled nursing facility, where the staff referred to her by her room number, and where few were invested in discovering what made life meaningful for her. Hospice certainly changed Lydia’s life, but the impact was far too late. Is it really too costly to offer a patient-centered approach at all stages of the care continuum? It makes you wonder what the true cost is when a life hangs in the balance.

Location, Location, Location: a Baby Step to Reducing the Hardship of Health Care Delivery

By Robert Broadway

Everyone knows what it means to take baby steps. These are the steps that guide us along life's journey. For many Americans, the footing along the path becomes treacherous when they need to access basic medical care for themselves and their families.

The solution to the financial burden is elusive; healthcare leaders across the country are taking baby steps to make it a little easier for everyone. One of those partnerships that started with a few baby steps is now delivering cost-effective health care and making a difference in Palm Beach County, Fla.

Bethesda Hospital is a not-for-profit hospital in Palm Beach County that has provided high-quality health services to our community for more than 56 years. Genesis Health Center is a Federally Qualified Health Center (FQHC) that has worked with Bethesda Hospital for several years. Our joint efforts were initially small, referring patients from our emergency department (ED) to Genesis for follow-up care. Genesis offered low-cost, high-quality care, and we worked together to develop an informal way to communicate to patients about how to set appointments at the clinic to access care. This partnership seemed simple enough: an ED and a clinic where basic care is delivered without imposing financial hardship.

All across the country, this same situation is occurring at hospitals and healthcare organizations, but in those same communities, individuals continue to be overwhelmed by the impact of financial and other burdens that revolve around health care. When we looked at the number of people actually scheduling primary care follow-up, it was minimal.

So we began listening to patients. Many worked and needed after-hours appointments. Paying copays and deductibles was a

major issue. Transportation and location were also barriers. After listening, we began to act. Genesis was located in a shopping center and was losing its lease. We had space on our campus 100 feet from our ED. What an opportunity. I worked with our executive team and others to bring Genesis to our hospital campus. Location, location, location.

Genesis relocating to Bethesda opened up many opportunities for collaboration. We redirected appropriate level 1 and 2 ED patients to Genesis in real time (location). We developed a more appropriate level of basic care (better care) at a lower cost (sliding fee schedule that is up-front and transparent). Patients were already here, eliminating the need to schedule a future appointment. And for those return visits, Genesis has evening and weekend hours. We redirected inpatient discharges who needed follow-up care to Genesis as they were leaving the building (location). We have an outpatient pharmacy, so patients can fill prescriptions without making another trip (location). It's working.

We have not solved all the issues relating to the financial burden of health care. But with our first baby steps, we have made connections with patients and provided convenient, cost-effective care. We have begun the conversation about value and continue to listen.

Discharge is Not a Dead End: Patient Navigators in the ED

By Meghan Checkley, MD

Often, the emergency department (ED) is a point of contact for patients who do not have a primary care physician or do not regularly seek health care services. When such people come in, I ask them, “Why tonight? Why now?” As a physician, I have struggled with this type of patient in multiple ways.

First, diagnosis is not always obvious without a certified technologist’s or specialist’s input. Second, it often takes time to identify a patient’s obstacles to care: Is the patient committed to his or her health? Will he or she be able to go to follow-up appointments, make the phone calls that are necessary to get through, pay for medications, and advocate for himself or herself? For a long time, I could find no easy answers to such questions.

Then, in came Patsy Smith, patient navigator extraordinaire. Patsy specializes in lowering barriers to care. My job focuses on identifying specific diagnoses, educating patients about their conditions, and determining a care plan, and her job involves reinforcing the information and simplifying execution of that plan. Navigating appointments and insurance issues is taxing and confusing for all of us.

In the ED, we pride ourselves as providers in getting patients in and out. However, although expediting flow is intended to help a hospital run efficiently and focus resources on the sick faster, it often distances patients who are not admitted from achieving their care goals. Patsy helps to reconcile this difference. The encounter with a patient who misuses the ED for primary care is transformed from a frustration to an opportunity.

Since starting in the patient navigator position three months ago, Patsy and her team have encountered more than 3,000

patients. When I recently asked her what she has found most surprising so far, she said, with a laugh: “Everything! I’ve had to make connections with every type of department. Many healthcare staff don’t know about each other’s services. I feel we open doors for providers as much as we do for patients.”

Patsy has visited drug rehabilitation and temporary housing programs, and next month she will meet with each managed care organization to identify its social workers and stopgap personnel. Such connections have been made before, but not systematically.

Nonetheless, Patsy admits that working in the ED has been challenging, partly because it is a place that is not known for follow up. “When I ask some people for their phone numbers to help with scheduling, they sometimes don’t want to give them to me,” she says. “Trusting is hard. It’s learned.”

Further, some patients don’t take advantage of the resources provided. Patsy’s team is cutting down on revisits for nonemergency needs, but they still must do so one person at a time. Most patients, Patsy explains, just need to know that someone cares that they get to their appointments.

I’ve learned in the ED that we, as providers, cannot worry about everything. Now, thanks to the patient navigator team, we have expanded our safety net and send patients home with their personal needs in mind. That’s an idea worth sharing.

Educated Healthcare Consumers? Happier Endings for Urgent Care.

By Bonnie Sheeren

My phone rang yet again with another frustrated, angry person dealing with a high-priced emergency department (ED) bill. As a patient advocate, I spend a great deal of time calming people down who are very upset when they receive an expensive medical bill after a quick trip to receive emergency care.

Typically, these patients have some urgent, yet minor, medical problems, and they have managed to go the wrong place for what they need. With some basic understanding and education about emergency care facilities, such stories might have had happy endings. Instead, these people now have a new source of stress in their lives.

This particular patient's problem began with a common misunderstanding. In 2009, to alleviate overcrowding in our EDs, the Texas legislature allowed the formation of freestanding EDs (FERs), facilities that are not physically connected to hospitals. Yet, no attempt was made to educate the public about the difference between the existing urgent care clinics and these newly formed FERs and when to use each type of facility.

Trouble starts when people go to the FERs for minor medical problems, thinking that they are going to an urgent care clinic. Instead of receiving a \$150 to \$300 urgent care bill for a minor problem, patients typically receive bills from FERs upward of \$1,200 for using the services of a facility that is open 24/7/365, with a board-certified emergency medicine physician available at all times. In addition, in the heat of the moment when people are searching for urgent or emergency health care, they generally fail to check their insurance coverage details, leading, once again, to frustration about the bills they receive afterward.

Even worse, for truly major medical problems, I learned that most people do not know the difference between the various levels

of trauma EDs, the levels of care for stroke EDs, or the different provisions for cardiac emergency services.

When I first learned of these common misunderstandings, I realized I had found my new mission. I went to work and dove into the details to sort out various scenarios here in Houston. I knew I wanted to educate people about what to do, to provide them with information that would help them make decisions early to avoid costly mistakes later—both medical and financial.

It has become my ongoing project to assemble all this information into a presentation aimed at encouraging people to plan ahead for emergencies, instead of just hopping in their cars and speeding away to the nearest healthcare facilities. As the late, great Yogi Berra said, "If you don't know where you are going, you'll end up someplace else." And, I would add, "with the wrong care and a large medical bill."

Only with a groundswell of educated consumers can our nation make its way to a better and brighter future in health care. Step by step, person by person, I hope to play a part in this movement to help people achieve the affordable medical care they need. It's the only way for all of us to truly live happily ever after.

A Patient-Centered Approach to Improving Quality and Decreasing Cost of Care

By Ryan O'Connell



MORE FROM THE FRONTLINES

THE COST OF DYING	13
IS THAT REALLY NECESSARY?	14
THE STRESS INVOLVED IN LIVING WITH A RARE DISEASE	15
THE COSTS OF ILLNESS	16
THE NEED TO KNOW IS POWERFUL	17
LOOKING FOR A LIGHT SWITCH	18
THE PRICE OF CERTAINTY	19

The Cost of Dying

By JaBaris D. Swain, MD MPH

It was probably the most awkward question I had been asked before, and I did not have an answer...

He was a middle-aged gentleman, neatly dressed—very simple and unassuming. He blended like a lifeless statue in the waiting area. What sparked my notice of him was his accompanying robust file, crammed with familiar pink discharge slips from the ED. He was clearly what we call a “frequent flyer”, but this would be his first visit in our surgical clinic.

I escorted him into the assessment room, exchanging the usual salutations as he edged onto the exam table, wincing with discomfort. His chief complaint read, “acute abdominal pain and constipation x 1 week.”

Vying to understand more about his issue, I asked, “Sir, how long have you had this problem?” Embarrassed, he lowered his head.

Silence.

I retreated and instead remarked, “Ok. Let’s start from today. Where do you have the most pain?”

Tenderly, his frail digits unbuttoned his shirt, exposing a wasted torso, which hoisted an extraordinarily distended abdomen. It appeared rigid and tense. I reached out to gently palpate it to confirm the realism of my observations. He flinched. His stoic affect instantly collapsed into an aching frown. Tears welled in his eyes. Something terrible was going on inside. Cancer.

He needed to be admitted and surgery would be very likely, if not too late. I was aplomb in my explanation of his condition, feeling proud of my thoroughness and precision. Yet, seemingly unengaged, he politely interrupted and asked, “How much will it cost to let me die?”

I paused. It was probably the most awkward question I had been asked before, and I did not have an answer. During my training, I was taught to order tests wisely, to avoid superfluous exams and to minimize inefficiency of resources; in spite of this, I had not ever stopped to think about cost in this context. In my mind, it was my duty to provide the best, quality care to extend life, foremost. Yet, his concern was different. How much would it cost to die?

Nothing.

Puzzled, my instincts led me toward urging him to reconsider, but he would not budge. As we talked further, I learned that he was unemployed, usurped from his job by a layoff; and his wife earned only a modest salary. His question was valid and real. I was helpless. Importantly, this gentleman made me pause to realize that as physicians, it is well within our purview to be mindful of costs and to think beyond pushing the envelope of life as far as it will allow when prescribing care. This gentleman represented just one of many who enter our health care system daily in advanced stages of disease—helpless, insolvent, unwary, and not prepared to face the raging costs of fundamental care. Rather than be overwhelmed with this burden, they would prefer to die. Remarkable.

Dr. Martin Luther King, Jr. captured the sentiment best in 1966 when he said, “Of all the forms of inequality, injustice in health is the most shocking and inhumane.”

Indeed, supporting a health care infrastructure where only a minority of individuals can independently negotiate the associated costs is an injustice in equity in its highest form, and it is an inhumane injustice that calls for our immediate attention. My colleagues and I must now assume the role of health care advocates and enter the discourse of public policy in efforts to better inform the decisions that impact the practice and cost of medicine. We are charged with this task beyond our will, but it is a task, which we must confront with fervent tenacity. In no uncertain terms can we any longer accept complacency on the issues that affect our patients and the way we provide care, including its cost!

Nevertheless, until the opportunity of real, indelible change arises, we shall all one day be indebted with the harsh reality of justifying the questionable benefit gained from the care we provide against the guaranteed financial burden.

In this instance, I failed.

The gentleman politely repositioned his shirt and declined care. The nurse practitioner gave him a script for an enema twice daily, and I never saw him again.

Is That Really Necessary?

By Ann Robinow

Attempting to alter the health care marketplace so provider decisions are based on patient value has shaped my career for the last 20 years. Often use of the health care delivery system creates a learning opportunity for me as well as the poor, unsuspecting provider of care. A recent experience was instructive.

A close encounter with a jungle rock while mountain biking sent my husband back to our cruise ship with a deep gash on his shin. Our ship's doctor cleaned it, stitched it and sent him to our room with antibiotic cream. Two days later, with red streaks around the wound and swelling puffing up around his stitches, his foot and ankle looked like a balloon with toes. A day of oral antibiotics followed by a few rounds of IV antibiotics on the ship got us to the end of the cruise and back to the states, but things still looked bad.

Landing near midnight, we headed straight for the ER for a dose of American medicine. Efficient service quickly led to a very pleasant doctor assessing the situation. "Yes" she said, "That's definitely infected. Let's start by getting an ultrasound." "Why," we asked, "Would we get an ultrasound?" She replied that we had just taken a long plane ride and it could be a blood clot. We said, "It looked exactly like this before we got on the plane. We have a \$5000 deductible and really would prefer not to spend \$300-400 for an ultrasound if it can be avoided." She said, "I'm sure it would cost a lot more than that!" and agreed that we could proceed without it.

Then she said, "Well, let's get him admitted." We asked why he needed to be admitted since they could clean up the wound and get him an IV antibiotic right there in the ER. She said they would watch him overnight to make sure he was doing all right. Having some idea of exactly how much he would be watched after midnight on a weekend, we suggested that since we lived 10 minutes away I would watch him and rush him back if things went south. She agreed that we seemed like responsible people who could be trusted to come back if necessary.

The next step was to remove the stitches and clean the wound.

This was going to be quite painful and the doctor said they had a new pain med that works really well. Then, finally catching on, she looked back and said, "On second thought, we can just add some morphine to his IV. That will work and it's a lot less expensive."

An hour later, armed with 4 prescriptions we headed home. We filled the oral antibiotic (\$16 at a local pharmacy) but skipped the antibiotic ointment (we already had this from the boat) and the Vicodin and Naproxyn since OTC ibuprofen was managing the pain.

The wound slowly healed and all is well with the injury, but certainly not with our health care system. We got great customer service, but how many thousands of dollars would have spent on this one event absent a few probing questions? How many millions of similar episodes occur every day across the country? Even for insured, middle class families, spending thousands out of pocket on a health care episode crowds out other needs, say a down payment on a car, a sizeable chunk of college tuition, or worse, the next few month's rent or mortgage payments.

Yet how many patients have the background and temperament to ask challenging questions, especially in the midst of a health crisis? Certainly, for the doctor all the incentives point in the direction of more care. A well-intentioned desire to be thorough combines with fear of malpractice and the fee for service system where erring on the side of doing more results in greater revenues for the care providers.

Patients can't solve this, even if they are armed with "skin in the game" and a handful of quality and cost measures. It has to be treating physicians and their teams who consider and discuss with patients the cost/value tradeoffs of their care recommendations. I believe most doctors would be sincerely concerned about the implications their recommendations have on their patients' financial health if they really understood what these expenditures meant to them. Hopefully, this particular ER doc now has an altered perspective.

The Stress Involved in Living with a Rare Disease

By Candace Lerman

At the end of 2014, I spent four weeks undergoing chemotherapy using the drug Rituxan. However, I didn't have cancer. I am battling a rare blood disorder called Immune Thrombocytopenia or ITP. After months of using steroids, which were destroying my body, my doctors knew we had to change direction. This set off a few weeks of absolute panic because Rituxan is not approved for treating ITP, a common problem with rare disease patients. It left me calling my insurance company sometimes up to five times a day, just to see if they would cover it.

Every time I called, I received various responses. My doctors attempted to reach out and were met with the same aggravation. The treatment would be my best shot at obtaining a close to normal life. I knew I would never be able to live like I was when I was healthy. If the treatment worked, I would be able to attend law school and gain some of the independence I lost after being diagnosed. I should have been focusing on preparing for the challenges of chemotherapy and getting myself together. There is an extreme need to be mentally sound when going through something like that. Instead, I was trying to decipher the endless black hole of medical billing and insurance regulations.

During the time that I was endlessly pursuing answers that no one seemed to have, I started having severe complications from ITP. I could no longer chase after my insurance company to get a final price on the treatment. I remember staying up a few nights the week I made my decision. It was pathetic; I had to choose between possibly putting myself into terrible debt for a chance at life and risking my health until I received an affirmative answer. I chose to go ahead with the treatment, putting my faith in my doctors and God that hopefully most of my treatments would be covered.

The treatments were hard to endure, but successful. I am glad that I went through it simply because I am now able to attend law school

in the fall. However, the panic attacks started a few weeks after my last treatment. These bills began rolling in for \$90,000 following each week I had an infusion. I started to get nervous, knowing I had absolutely no way of paying that off. ITP had already drained me financially, between six days in the hospital, tens of thousands of dollars in blood tests and multiple doctor visits. My savings account was abolished, and to top it off I lost my job. I started to feel hopeless again, when I should have been celebrating.

By nothing short of a miracle, my insurance provider ended up covering a portion of my treatments. I received a final notice of what I owed well over four months after I completed the treatments. I'm currently trying to budget my expenses so I can pay off the remaining debt before I start school. It made me angry that despite calling and requesting information, e-mailing supervisors and those I was told would have the answers, I waited until a final bill came to be enlightened. The stress brought on by the unknown is terrible, especially since I am already at my wit's end trying to manage my life as a newly diagnosed rare disease patient.

My hope is that in the future, insurance companies can create the tools necessary to answer questions like mine. It is completely unnecessary for a patient who is undergoing a major health event to have to stress over unknown costs associated with treatment. The surprise bill at the end shouldn't provide relief or panic; it should just be an expected part of the healthcare process. Patients like myself continue to strive to be informed and active within the healthcare community. We expect insurance companies to follow our lead.

The Costs of Illness

Monica Williams-Murphy, MD

“Unless you’re a Warren Buffet or Bill Gates, you’re one illness away from financial ruin...”

~Dr Steffie Woolhandler (CNN interview, 2009)

Mrs. Sandra Jackson knew that she was no Warren Buffet. She knew that she was no Bill Gates. Instead, Mrs. Jackson knew that she worked two jobs, 7 days a week to support her family. So, she hid her breast condition for a better time, another day. She would ask herself, which was more important: going to a doctor or buying her children dinner? For a true mother, the answer was easy, but the consequences were not.

Months passed and Mrs. Jackson worked harder. She was working against a clock which was hidden from her view and yet, somehow instinctively, she knew the time. She came to the ER at the end of the last shift she ever worked.

She lifted her blouse and turned her head away, in shame. But I did not cringe, instead I delicately examined the breast which had the appearance of melted wax, disfigured by a flame. “Do you hurt?” I asked, knowing that pain may take many forms.

“Only my bones,” she said as a few tears escaped her proud eyes, cast upward trying to look beyond the room-- trying to look back in time or into an alternate reality, anywhere but here, anywhere but now.

I had hoped that her bones were aching from the back-breaking labors she performed day in and day out for her family. I hoped that her pain was that of a worker-warrior, those who push themselves in ways that make the rest of us appear weak and flaccid. I hoped that her pain was anything other than what it was--metastatic breast cancer.

After I confirmed the diagnosis, we sat in silence. I had not told her anything that she hadn’t already known. But, what I said was much less important than what she had to say- the story leading up to that day. Mrs. Jackson told me of her struggles, her fears and her choices: big doctor’s offices with big bills to match, bad news that she could not afford to fight, and children whose own health and well-being depended on what she did or did not do in any given moment.

As she spoke, I entered her story with her and could feel her life as my own. I took off my white coat, and for a while, we were just two mothers, sitting together sharing a very difficult journey.

In the end, I did not fault Mrs. Jackson for her choices- instead, I understood her plight. Some may have called her choices “poor” but, I called them “heroic” in a system that proved “poor” for someone whose financial status carried the same name. You see, Mrs. Jackson knew that she was no Warren Buffett. She knew that she was no Bill Gates.

However, Mrs. Jackson did know the cost of her illness...that it was far beyond her means. So, it costed her life.

The Need to Know is Powerful

By Robbie Fenster, MD

“I’d really feel better if we got the MRI,” Ms. James said. “I understand you think it’s a migraine, but I want to know, just in case. Wouldn’t you?”

Ms. James and I sat in her darkened hospital room—the light bothered her eyes and exacerbated her headache. She was a dialysis nurse with many years of experience in the healthcare field, and I was a first-year doctor trying to convince her that she was most likely suffering from a migraine and did not need additional tests.

Ms. James had woken up the morning before with very concerning symptoms. Her head hurt terribly. She got out of bed, but she felt nauseated and had to lie back down. She thought she needed her morning coffee, but she felt too sick to go downstairs to make some. Her headache had worsened, and she began to notice shooting pains in her left arm. She was scared. A few hours later, her daughter arrived to find her mother’s speech was slurred. The daughter called an ambulance.

By the time Ms. James reached the Emergency Department, her speech had improved, but her headache remained. The fluorescent lights bothered her, and the loud noises of the hospital grated her nerves. A neurology resident was called to evaluate her. He felt that she was most likely experiencing a migraine and recommended that she be given some medication to help with her pain. He thought it was possible that she could have suffered a TIA—a transient ischemic attack, in which the blood supply to a part of the brain is temporarily blocked—but he felt that this was a less likely possibility. He did not think she would need an MRI scan of her brain unless her slurred speech returned.

The craft of medicine requires doctors to constantly manage probabilities. Indeed, the weighing of likelihood is built into our methodology: we hear patients’ stories, list possible diagnoses, and then rank them according to probability, creating “the differential diagnosis.” We order tests to rule these possibilities in or out and gradually refine the list until one diagnosis remains. This approach is systematic, but when followed too rigidly leads to unnecessary

tests that inflate the cost of care. Situations occur very frequently in which tests are ordered to eliminate possibilities that are highly unlikely (the “just in case” scenario), or in which the added knowledge of the test would not affect our therapeutic strategy, but we feel a “need to know”.

This latter situation arose with Ms. James. We had two most likely possibilities—a TIA and a migraine—with only an MRI that might help us differentiate between them. However, because Ms. James had additional medical problems like hypertension and diabetes, she was already being treated with the recommended therapies for secondary stroke prevention. In other words, ordering the MRI would probably have no impact on her medical care. It would only satisfy the “need to know”.

The need to know is powerful, on both sides of the doctor-patient relationship. In the October 17, 2012 issue of JAMA, Jutel and McBain point out that our society places a high value on certainty in diagnosis and that this fascination with certainty may have harmful consequences, leading to unnecessary treatments or to tests that do not influence patient care. Sitting in the hospital room with Ms. James, who was anxious about her diagnosis, I felt the power of the drive for the “need to know”. It felt as though I was withholding something from her by telling her the reasons an MRI would be unnecessary. These conversations with patients are not easy, particularly when patients are anxious about their diagnosis, but if we hope to control the cost of healthcare in this country, they are of utmost necessity.

Ultimately, Ms. James got her MRI, which was negative. Her persistence, our discomfort with the uncertainty, and our worry about hard feelings and the omnipresent specter of litigation all played a role. She felt better knowing. But the decision still nags at me. If we had been able to convince her that fewer tests actually meant better care, perhaps we all could have reached a better outcome.

Looking for a Light Switch

Benjamin Robbins

The Saturday after Sandy hit, I was the medical student in a Cambridge, Massachusetts emergency room. Around the time my shift started, Andrew, a man about my age, couldn't bear the pain in his nose any longer. A few days before coming to the ED, he'd left behind his flooded, powerless Brooklyn apartment seeking refuge in his childhood home of Cambridge. He outcompeted the crowds to become part of the lucky handful of New Yorkers to catch a bus out of town.

Andrew had friends near Cambridge, because until a few months ago he worked for a company based in Boston. He liked the job, because it provided "good pay and benefits with enough time off to see friends." One day everything changed. While biking to work, he'd just crossed over the Charles River when a car swerved into his path. He smashed into the side and flew over the hood, landing face-first on concrete. His teeth were shattered, and he'd need surgery to repair fractures in his face. Insurance covered his bills until it came time to put in new teeth. His policy excluded oral surgery. If he wanted teeth, he'd need ten thousand dollars.

He plainly told me that after the accident he started looking for jobs that provided health insurance inclusive of oral surgery. "I was still single," he explained, and "I figured it'd be easier to meet someone if I had teeth." In a stroke of luck, he landed a dream job in Manhattan with the right benefits. There was a catch, however; health coverage wouldn't start for a year. Believing it unlikely that something else would happen to him, he signed on and moved into an apartment near Prospect Park in Brooklyn.

A few months later, we met. He was in a hospital bed, and I was standing awkwardly behind his physician. "What brings you in?" I asked, trying to ignore the red bulge emerging from his nostril. "I'm a pretty hairy dude" he said, referring to his bushy beard. "I think I have an ingrown hair." Two days earlier he'd noticed a "pimple" inside his nose. Then another. They grew and became painful over the next day. They'd gotten so big that his nose looked crooked. With his recent facial injuries, we'd need a CT

to see behind his swelling. "I've got to pay this out of pocket, so could you ballpark how much that costs?" We couldn't. "Are we talking about like \$10 or \$10,000?" We didn't know that either.

I felt anxious. All my classes on clinical outcomes, and the ballooning costs of healthcare, and I couldn't estimate the cost of a CT, or the risks of not doing one at all. I guessed the doctor had the same thoughts, and was eager to see how she'd respond. We heard a distant alarm. "One second" said the physician, leaving the room. Suddenly I was alone with Andrew and his terrifying questions. He asked "What would you do in this situation?" I had no idea. I mumbled something about him needing to make a decision with limited information, but I'm quite certain I provided nothing useful.

Thankfully, before Andrew realized that I wasn't saying anything, the doctor returned carrying a thick 18-gage needle. "Ok, decisions on the CT?" Andrew responded "I'm gonna pass." A few seconds after explaining how we'd lance the "pimples" in an effort to drain them, the needle was inside Andrew's nostril. He gave a loud, shrieking moan as the needle punctured skin. A few seconds later, he erupted with the most violent sneezes I've seen, and it was over. The doctor said "it'll be really important to return in a couple days. You're welcome to come back here or see a nose specialist." Andrew asked knowingly, "You aren't sure of the cost of either visit, right?" She responded "I'm sorry I don't know the cost of an ED trip, and I called an ENT physician for the price of an appointment with him. He didn't know." Andrew didn't come back.

I called him a few weeks later to follow up. He apologized for not coming back, saying "it wasn't bad enough to potentially pay thousands of dollars for another visit." We talked about the frustrations of that night. He summarized his experience, saying "it felt like I was in a dark room. I kept looking for the light switch, but never found one."

The Price of Certainty

By Tom Peteet, MD

Mr. J was as close to a typical sixty year-old patient as possible, wary of doctors and selective in when he took his blood pressure medications. On a sunny Thursday, he woke up nauseated and called an ambulance. During evaluation in the emergency room, his blood pressures reached atmospheric levels (nearly 300 systolic). He began seizing, which soon stopped and was transferred to the ICU. As the admitting resident, I dutifully went through the potential causes of his elevated blood pressure: medication noncompliance, surreptitious cocaine use, and even the zebra diagnosis of a pheochromocytoma. As for the seizure, I held firm on the diagnosis of PRES, an acronym for posterior reversible encephalopathy syndrome, an under diagnosed condition of abnormal blood flow to the brain in the setting of high blood pressure.

Mr. J was on course for a typical hospital admission. We would run a battery of tests, determine a singular diagnosis for his problem, and send him home on treatment. The hospital would be reimbursed for his coded diagnoses of hypertension, PRES, seizure, and he would have close follow-up with specialists.

If Mr. J was a typical case, our discussion of costs and appropriateness of testing was not. Despite a resurgence of “cost-consciousness” within medicine, the word cost rarely comes up in the ICU. Much of the discourse around cost and of the Choosing Wisely Campaign is an effort to avoid unnecessary tests in clearly defined circumstances. However, Mr. J’s case shows us that the vast majority of clinical decisions live in a gray zone of appropriateness. On rounds, the question came down to this: does he need a brain MRI and angiography (MRA) to “prove” he has PRES? The clinical history seemed to support the diagnosis, and the study could potentially offer limited prognostic information. Also, in the highly improbable scenario the patient did have a small stroke, we would see it on the MRI. What is the value we place on this minimal increase in certainty? According to the Healthcare Bluebook, the cost of both studies is \$1206.

Taking a step back, I wondered about our zeal to “prove” a diagnosis. Physicians so frequently frame clinical questions around diagnostic proof that we forget this is not the only way. Why not frame clinical questions around appropriateness, cost, or even risk-benefit to the patient? Context matters. In settings like the emergency room or ICU, ruling out the worst is highly valued. If he continued to be stable after a few days, the diagnosis would be PRES by exclusion, and we would all save time and money. Similarly, in one month, if Mr. J remained fine, his primary care doctor would not rush to get an MRI. But he was in the ICU, we needed an answer, and a test offered us the psychological boost we needed.

Mr. J walked out of the hospital five days later on a different regimen of blood pressure medications. He thanked the staff profusely, who in turn, felt they provided excellent care. Each actor behaved rationally: the patient and clinician to get a diagnosis, and the hospital to generate revenue. The system, however, behaved irrationally, to the cost of the public and also the patient. Despite a confirmed diagnosis of PRES, Mr. J will follow up with two specialists to verify the results of other rare causes for high blood pressure, again generating revenue, visits, and a minimal gain in certainty.

As a physician in this structure, I struggle to maintain hope, as thoughtfulness contradicts rationality. For Mr. J, I pushed against getting the MRI because I valued diagnostic utility and system costs over diagnostic accuracy. The system pushed back. The neurologist highly recommended the test, the ICU attending changed over, and the fellow “needed to rule out a mass.” Considering the cost and appropriateness of each test is hard work, and too great a task for one person. While I am skeptical of top-down change, I take solace in the ability of clinicians to think complexly: to weigh accuracy alongside cost, risk, and benefit. In the gray areas of medicine, we as clinicians would do well to ask and wrestle with the question, “What is the price of the certainty we seek?”

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