FIRST, DO LESS HARM

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FIRST, DO LESS HARM

Confronting the Inconvenient Problems of Patient Safety

Edited by Ross Koppel and Suzanne Gordon

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We dedicate this book to the physicians, nurses, pharmacists, researchers, epidemiologists, and others who work so hard to create safe treatment of patients. We also dedicate this book to patients and caregivers who have lived with both illness and patient safety failures.

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FIRST, DO LESS HARM

Introduction

Suzanne Gordon and Ross Koppel

Vignette 1

A few years ago my wife, Meg, had major surgery at a highly regarded, fully wired hospital. After surgery, Meg was wheeled up to the floor with her assigned room. Computer displays at the nurses' station indicated she had left the post-anesthesia care unit and was now on her floor. I was in the lobby waiting to be told of her room assignment. After about forty-five minutes I became alarmed. I searched the probable hospital floors and found Meg shivering, dehydrated, and alone by the elevators. I ran to the nurses' station down the hallway and asked why she'd been left there so long. They responded that they knew she was being sent up but didn't know she'd been left in the hallway. We hustled her into her room, covered her with blankets, and gave her ice chips. As a scholar of hospital workflow and health care information technology, I understood what happened, but I was still enraged.

Had I not intervened, it's possible that someone would have noticed her. It's also possible that someone would not . . . or that someone would have noticed her and assumed she was calmly waiting for her transportation. (Ross Koppel)

Vignette 2

Joan Smith (a pseudonym) is a nurse at a major American teaching hospital—one that has pioneered patient safety initiatives. She's informed by her

manager of a new improvement that allows charting (recording patients' medications and vital signs) in each patient's room, rather than at the central nurses' station. New computers have been installed in each room. Smith is eager to benefit from this improvement, although she finds it odd that none of the nurses was consulted on the placement of these new computers.

She enters one of the newly configured rooms, starts using the computer, and is slammed in the back of the head by the door. Much to her dismay—but perhaps not her surprise—the computers have been placed where the door opens into the room. So if the door is opened while a nurse is standing at the computer, it will whack her in the neck, head, or shoulder. Worse, some of the questions the nurse asks patients are very personal; closing the door is both appropriate and required.

At the next nurses' meeting, Smith points out that the unit's goal of reducing workers' compensation claims will not be aided by the placement of the new computers. More important, she asks why no bedside nurses were included on the team designing computer placement. When there is no response, she sighs and simply states, "Well, there go our compensation claims and our shoulders." As of this writing, the situation has not been addressed.

Vignette 3

The cardiologist T.K. is seeing a patient who needs both a CT scan and an MRI. He uses the Computerized Physician Order Entry (CPOE) system to order both tests and is delighted to find that both tests have very similar ordering templates (user interfaces). Unbeknown to this physician, however, the CPOE system does not actually transmit CT scan orders to the radiology department. A scan is neither scheduled nor administered. CT scans, he later learns, must be ordered via a different computer screen, but there is no indication of this at the time of ordering. For the patient, this means that finding his problem, and therefore starting the needed treatment, is delayed by weeks. The cardiologist did not remember ordering both tests and only reconsidered a CT scan when the patient was in extremis.

Although the saying is attributed to Mark Twain, it was Charles Dudley Warner who said everybody talks about the weather, but nobody does anything about it. By contrast, everyone seems to be doing something about patient safety. Every day our email includes messages announcing a new initiative launched by the Institute for Health Care Improvement (IHI)—one of the leading organizations in the patient safety movement—or a conference hosted by another safety group. Books by patient safety advocates

such as Atul Gawande and Peter Pronovost now make the *New York Times* best-seller list. As if to highlight the importance of patient safety, President Barack Obama named the founder of a major patient safety organization, Dr. Donald Berwick, to be the administrator of the Centers for Medicare and Medicaid, although political pressures led to his resignation.

Yet despite more than a decade of highly focused attention on patient safety, anecdotes like those we have related abound. Collected in quantitative studies, these anecdotes paint a sobering picture of the state of patient safety both in the United States and globally. In 2010 several reports from the Agency for Healthcare Research and Quality showed that the rate of bloodstream infections could be reduced dramatically by a series of simple steps (the so-called checklist), but at the same time, that agency reported, such infections had increased by 8 percent in one year throughout most of the nation.[1]

In the same year, two professors from Case Western Reserve published an article in the *Berkeley Technology Law Journal* with even more distressing news.[2] Doctors, the authors, warned, should be wary of the promise of electronic medical records. Software bugs, lack of adequate training in complex technology, incessant warnings of drug interactions with no real threats, and errors that generate the wrong output create significant patient safety hazards for which physicians may be held liable. As other authors, including one of the editors of this book, have pointed out, health care technology may be a bullet, but it does not seem to be the silver one so many experts have promised.[3]

We have been working on this book for over four years. Some of the essays in it were begun that many years ago. When we asked authors for updates, many were able to provide more recent references, but alas, the progress of patient safety was seldom the reason for the updates. Despite the increase in funding and attention, the authors primarily included more recent studies and newer documentation of patient safety's unmet challenges.

Please don't misunderstand our intention. We know there has been movement on patient safety—numerous and important pockets of improvement.

The problem is, as we shall see in this book, that too many of these pockets are isolated, and the sum of the parts does not seem to constitute an impressive whole. Many wonderful initiatives and activities often seem disconnected from, or undermined by, actions taken by the very institutions in which they have been pioneered. Institutions don't just fail to learn from one another; they may not even connect—and learn from—what is going on in one unit or discipline to what is going on in another. Across a single

hospital or health system, or throughout a region, or in the entire nation, it often seems that the proverbial one hand not only doesn't know what the other is doing but is deliberately canceling out the other's efforts as well.

Here's a classic example. A hospital participates in a prestigious foundation's initiative on improving care. The project, according to the foundation's website, has done "great work" to improve care on medical-surgical units.[4] Suzanne Gordon is observing on a hospital unit. She sees photocopied yellow sheets—with an image of a traffic sign triangle and in it the words "No Passing Zone" posted on every patient room. What does this mean, Gordon asks. The nurse accompanying her explains that this is an important part of the unit's safety initiative that has been implemented on the unit. Everyone—from unit secretary to janitor—has been told not to go by a patient's room without looking in to make sure nothing untoward is happening. "For example," she explains, "if a frail ninety-eight-year-old lady is trying to climb over her bedrails, you don't just look in, see it, and walk by. You do something about it."

"That's great," Gordon commented and then asked, "Does that apply to physicians as well?"

"Oh, no," she answers, apparently without noting the irony, "only to hospital employees." So the nurse, the janitor, the unit clerk—all have a duty to rescue the patient. But on a unit funded by a leading health care foundation and implemented by a leading patient safety group, the physician, who is supposed to be the captain of the ship/team, is exempt.

Or take the issue of physicians' neckties. We now know that those carefully knotted, handsome cravats, so gracefully dangling over the front of a man's shirt, are the perfect vectors for germs. A male physician leans over a patient to examine a wound or to listen to chest sounds, and his tie brushes against the patient, the gown, the sheets. Now covered in germs, he moves to the next bed and brushes against another patient. And then on to the next. Studies have made clear how harmful this can be—so harmful, in fact, that in 2007 the British National Health Service initiated a "bare below the elbow policy," banning not just ties but long fingernails, jewelry, and lab coats.[5] In the United States, however, ties are still dangling from doctors' necks, lab coats are worn throughout hospitals, and so are jewelry and long nails, even though U.S. hospitals are trying to reduce infection rates.

Patient safety initiatives come and go, some contradictory, many isolated or fragmented by departments or occupations. Some medical services or disciplines are largely ignored. And then there is the disconnect between management and staff, and between management and unions—all important "stakeholders" in patient safety. Efforts requiring comprehensive approaches

are introduced in piecemeal fashion; many patient safety programs are unnecessarily entangled with modern health care information technology (HIT), whereas others that could benefit from HIT are bereft of its assistance.

This book is an exploration of why patient safety is advancing at what seems to be an almost glacial pace, despite the often vast and determined efforts of health care workers and managers. A collection of essays from prominent researchers, scholars, and even patients, this book aims to identify some of the gaps in the patient safety movement, the disconnected dots that do not coalesce despite decades of hard work and billions of dollars. It also identifies concerns that have not been integrated into the patient safety discourse or agenda of more established groups.

Although the chapters deal with a variety of issues, a number of themes unite them. The first and most important is the fundamental contradiction between two of the imperatives driving our health care system: safety and cost. This contradiction is perhaps most acutely felt in the United States, where the health care system must address the requirements of many separate insurance companies with differing priorities and patterns of coverage. Frequently patient safety becomes a casualty of the drive to cut health care costs and the accompanying failure to understand that ensuring safety is—in and of itself—a cost-saving activity. The essays in this book illustrate some of the predictable irrationalities of that contradiction. As Rosalind Stanwell-Smith points out in "Too Mean to Clean," and as the chapter by Peter Lazes, Suzanne Gordon, and Sameh Samy makes clear, saving money by outsourcing cleaning often results in dirtier hospitals, more hospital-acquired infections, and the additional costs of those unnecessary illnesses. Further, authors Sean Clarke, Christopher Landrigan, Alison Trinkoff, and Jeanne Geiger-Brown document how increased workload and schedules that prevent clinicians from getting enough sleep increase both errors and costs.

The anecdote recounted by the RN earlier in this chapter depicts the predictable irrationalities that result from the disconnection between cost, safety, and the work environment. The nurse who had her head slammed by the patient room door was on a unit concerned with both patient safety and the cost of worker compensation claims. But no one connected the dots when locating the nurses' computer stations. As a result, as the nurse commented sarcastically, "there go our worker's comp complaints and our shoulders."

Much of the tension between patient safety and the market discourse dominating health care is embodied in the idea of patients as "customers." Patients are not, in fact, customers making informed choices based on full knowledge of their best options. The role and model of professional and caring clinicians is supposed to protect patients from unwise decisions.

But instead we have a marketing metaphor that largely replaces professional autonomy with a concern with salesmanship and misplaced customer satisfaction measures.

The market model stands in contrast to the ethical dynamic at the heart of patient safety. Patient safety begins with the injunction attributed to Hippocrates: the physician (or hospital) should "first do no harm." When, however, doctors, nurses, pharmacists, hospitals, and administrators are obliged to consider their services as competing product lines within their institutions and told to view one another as competitors and their patients as customers, it is hardly surprising that the logic of the market may interfere with the ethics of the healer.[6]

The second theme of this book concerns the place of frontline workers in patient safety discussions and initiatives. At the core of many of these chapters is an analysis of what happens when frontline workers are neither consulted nor involved in the planning, implementation, evaluation, and refinement of patient safety initiatives. Whether they be physicians and nurses who will be using health care information technology, or cleaners who are given insufficient supplies to do their jobs, failing to ask workers to identify safety problems and their remedies represents another hidden problem and cost. Ross Koppel and his colleagues contrast the overwhelming faith in health care information technology with the reality of its use. They discover that lack of on-the-floor observation encourages the creation of software that does not meet the needs of clinicians and often increases the dangers of medication errors in ways that have been systematically ignored, deflected, or intentionally hidden in nondisclosure clauses of vendor contracts. They describe the ways in which software vendors fail to incorporate the often desperate requests of physicians, nurses, and pharmacists who struggle with screen displays that obstruct rather than aid in patient care. Koppel and his colleagues' discussion of the contradictions and inappropriate models underlying patient safety initiatives is echoed in the essay by Joseph Bugajski, a noted authority on IT. Bugajski's sardonic tale of his medical mistreatment involves professional blindness, HIT, foolish routines, and, as the title relates, "the data model that nearly killed me."

Health care settings are messy, often unpredictable, emotional places, and they depend on dedicated workers. Running a hospital is not like running a factory or even a complex power plant; there is no design protocol that will handle all the resulting contingencies. If safety is primarily the province of experts or managers who make pronouncements in public spaces, it nevertheless remains the task of workers who inhabit private spaces.

As Lazes, Gordon, and Samy point out, the failure to consider seriously the input of frontline workers (particularly those low on the health care ladder) is connected to another issue identified in this volume: the impact of status and hierarchy on the safety of patients. On this point, we include Kathleen Burke's brief and insightful essay on how Medicare's rules for administering medication fail to take into account how medication is actually administered in hospitals. When actual work processes are not understood, or when, as Gordon and Bonnie O'Connor argue, some members of the health care team are considered the "mindless" servants of the mindful elite, safety will inevitably fall through the cracks. Similarly, as Gordon writes in "On Teams, Teamwork, and Team Intelligence," even some of the most promising experiments in patient safety are defeated by those who are so concerned about maintaining status hierarchies that they are blind to their implicit but contradictory messages.

As we write the introduction to this book, the world has just celebrated the one hundredth anniversary of the death of Florence Nightingale, one of the first patient safety pioneers. Nightingale was also one of the first "systems thinkers" in health care. She recognized the importance and interconnectedness of every detail of patient care. Nothing and no one was too trivial to command attention and scientific study—from the cleaning of the ward floors, linens, and uniforms, to the food preparation, to the way supplies were maintained.

Nightingale knew that systems thinking isn't just about the big-ticket items; it involves understanding how the components of the system interact.[7] A modern Nightingale would understand that if doctors and nurses have no time to wash their hands, or if outsourced cleaners aren't taught enough about infection control, then they will spread infection from one patient to the next. That is why another concern the authors of this book share has to do with the common but false dichotomy between patient safety and workers' health and safety. Dr. Christopher Landrigan, a renowned researcher and advocate for regulating physicians' working hours, is joined by Alison Trinkoff and Jeanne Geiger-Brown in highlighting the connection between caregiver exhaustion and threats to patient safety. When RNs and MDs are overtired, they are in jeopardy, and so are their patients. Errors go up, and so do exhaustion and stress-related illnesses. Similarly, the skeptical and increasingly cynical nurses we meet in the chapter by Lazes and colleagues are disenchanted with their hospitals' safety efforts because they feel that their concerns about workloads and work safety are ignored, or even attacked. You don't have to be a safety expert to recognize the irrationality of turning health care workers into patients. The chapter by nurse-researchers Linda

Treiber and Jackie Jones unites many of these themes and asks us to consider something that is too often forgotten in much of the discussion of patient safety. That is the impact of errors not only on the patients who suffer from them but also on the nurses and doctors who are links in the chain that led to the errors. Nurses and doctors who are institutionally and/or publicly identified as having committed errors tend to be scapegoated rather than helped. In fact, health care workers are profoundly distraught over any errors they have made. Their careers, their mental—and sometimes physical—health are also casualties of institutions that do not give sufficient attention to the *systemic causes* of patient safety failures but instead rely on overworked staff and hypervigilant clinicians.

The concluding chapter, by Koppel, Gordon, and Joel Leon Telles, presents twenty-seven paradoxes, ironies, and challenges of patient safety. It considers many of the major reasons why it is so difficult to ensure the unharmed passage of patients through health care facilities—and why our efforts are so frequently contradictory or misdirected. As they note, even the concept of "avoidable" errors is a contested terrain of economic, professional, ideological, ethical, and even epistemological disputes.

The catalogue of disconnected dots mentioned earlier is certainly not exhaustive. Nor are the issues we tackle. Every discipline or occupation could have its own chapter. We do hope that these twelve essays stimulate a much-needed discussion.

Chapter 1

The Data Model That Nearly Killed Me

Joseph M. Bugajski

In 2009 the U.S. government appropriated about $38 billion for health information technology and to create a program to digitize and network health information.[1] The appropriation law also defines rules for some health information standards and systems. It does not, however, explain how to test the validity of the information used by those systems. I argue that these prescriptions for a Nationwide Health Information Network (NHIN), though necessary, are insufficient.

During the last week of January 2009, a faulty electronic networked health information system nearly killed me despite its being run by two advanced, state-of-the-art medical facilities. This will come as no surprise to health care IT experts because health information is inherently complex, medical science develops extraordinarily rapidly, patient interactions are intensely personal, and the number of data types and sheer volume of health care data explode prodigiously with new tests, instruments, and treatments.[2] Because the purpose of an NHIN is data exchange, and data exchange requires a good model of the data being exchanged, and rapidly changing data make modeling intensely difficult, an NHIN is at worst infeasible and at best an extraordinarily difficult undertaking.[3]

My near-death experience at one of the best tertiary medical centers in the world, equipped with modern electronic health information systems, illuminates the chasm between the NHIN vision and its reality.

Treatment Saga

My ordeal began on Sunday, January 25, 2009. I returned from church, ate breakfast, and sat down in my favorite chair to read the paper. Within an hour, my lungs were causing me so much pain that I had to lie down. Two hours later I had a 104 degree fever, a not-working-so-well emergency asthma treatment regimen, and a tortured conversation with my by then very concerned allergist. I was on my way to urgent care. My wife reluctantly agreed to drive me to the clinic affiliated with my allergist's office rather than a closer-by clinic, because, I entreated, the farther-away, affiliated clinic would enter the attending doctor's report and any test results into my electronic health record for my allergist to review on Monday morning. (Okay. Low blood oxygen was messing with my brain, but it seemed a good idea at the time.) Thus, day one of a near-death experience began.

Urgent Care

The nurse who escorts me into urgent care asks me for my doctor's name. I tell her my allergist's name. The nurse argues that she wants to know the name of my primary care physician. Of course, that information is in my electronic medical record, which she can readily access. The nurse next requests that I relate my medical history, which information is available in my electronic health record (EHR). Next, an attending physician asks for my doctor's name—no, not my allergist, my internist—and tells me to please relate my medical history. Never mind that (a) I provided this information to the nurse only moments ago, (b) I can barely breathe, (c) I have horrible pain in my lungs, (d) I have a high fever, and (e) the requested data already are in my electronic health record. Perhaps, I think, these professionals must verify my data—regardless of whether or not my brain wants more oxygen. I explain to the nurse and doctor that my allergist, who is a specialist in allergy and immunology, and who also has a Ph.D. in pulmonary medicine, wanted me to receive certain treatments. The attending physician at urgent care says that I may have pneumonia. I say that I also have severe asthma. She smiles politely and walks away.

By and by the attending physician requests an X ray and a blood test. I ask for pain relief medication (the correct prescription is in my electronic health record). The doctor prescribes two Tylenol tablets, which do nothing for the pain. Hours go by. The X ray shows no pneumonia, says a radiologist. The attending doctor orders an intravenous antibiotic to help me deal with the infection and asks if I feel better. I say, "No, not really." Do I want a breathing treatment? "Yes, that would be good." I am sent home.

During my visit to urgent care, starting about 1 PM and continuing until 7 PM, my respiration is double to triple its normal rate. My lungs are bags of pain that trap CO_2. I have a high fever. I want to die. Despite the existence of a well-maintained electronic health information record in a state-of-the-art health information network, I am not treated for asthma aggravated by a lung infection as my medical history clearly and unambiguously indicates I should have been.

Doctor's Office

I cannot sleep during the night following the visit to urgent care. I am unable to breathe without intense pain. My respiration rate remains much higher than normal. But my fever has broken. First thing in the morning, I call my allergist's office. My allergist's nurse returns my call around 2 PM. She says that the doctor wants to see me at 4:30. He believes that I am still in serious trouble. My wife collects my medications (bless her, because later these would keep me alive) and drives me to my doctor's office.

My allergist and his nurse do not take my medical history. I lie on a gurney in an examination room, hooked up to monitors and supplemental oxygen. My doctor listens to my lungs as I labor and cough my way through a few breaths. He observes my respiration rate. He waits awhile. He repeats these observations thrice. Around 5:30 my allergist says that I am too sick to return home and he wants me admitted to the hospital for continuous observation. I object. He replies that I may die if I go home. His nurse calls for an ambulance. No, my wife cannot drive me a mile and a half to the hospital—the doctor says this would be too dangerous.

Ninety minutes pass before the ambulance arrives. My allergist spends the intervening time preparing a four-page memorandum giving my medical history, my current condition, and a recommended treatment plan. He also telephones the admitting physician at the emergency room, where I am heading next, to discuss my medical issues. My allergist then entrusts this information to the ambulance attendant.

ER and ICU

Once I am in the ambulance, the attendant asks me to give my medical history, including allergies and medications. This information he enters into a multipart form. When we arrive in the ER at the medical center affiliated with a world-renowned university, someone behind a desk calls me "asthma" then tells the ambulance attendant to park me in a hallway. The attendant

delivers his report, oral and written, to the triage nurse, who by then is examining me. The attendant tells the triage nurse that he brought a written report from my physician for the admitting doctor to read. The nurse instructs the attendant to deliver his reports to a person behind a nearby desk. She says the information will be put into my chart.

I remained in the ER for twenty hours before being admitted to the hospital. Throughout my stay, I was hooked up to network-attached monitors that incessantly sounded alarms to which no one responded. I was asked eleven times to repeat my medical history, medication, and allergies to as many different medical professionals. Seven doctors who saw me each asked similar questions. Five of the doctors were never to be seen again. All the doctors mumbled something about putting their findings into the hospital's EHR system. Later I learned from the nurses that most did not do so. No one read my allergist's detailed report about my condition and health history.

I was moved from the ER to an ER holding room for admitted patients, back to the ER, to and fro to other departments for tests, then finally to an ICU. I was visited by nurses and technicians who pushed laptops mounted on wheeled sticks (COWs—computers on wheels). They checked my vitals; asked me questions about my history, medications, and allergies; and entered findings into the hospital's electronic medical record using the laptops mounted on wheeled sticks.

I asked every nurse and doctor who met me for medication to relieve the intense pain from my lungs, and was told I would receive it. Each claimed that he or she would note the order in my electronic medical record. No one did until about fourteen hours after I arrived, when, during the middle of the night, one thoughtful ER nurse finally found a doctor to authorize giving me the oft-approved but never delivered pain relief medication.

Data Lost and Not Found

No one in the ER or, later, the ICU, knew about, or could find, my allergist's memorandum describing my medical history, current medications, and treatment plan. My wife eventually called the allergist's office to obtain a fax copy for the ICU. No one ever mentioned reading the fax copy, although an ICU nurse confirmed its receipt. The list of persons who denied knowledge of the memorandum included the on-site doctor (the "hospitalist"), who represented the same clinic as my allergist. The hospitalist could view my electronic health records on-line from the hospital, but she ignored this rich source of vital information about my condition, preferring instead to come to her own (unbiased?) conclusion.

One heroic medical professional, the first nurse I met in the ICU, worked to create a consistent record of my condition, allergies, and medications in the hospital's electronic health information system. She spent over an hour searching for previously entered data, correcting errors, and moving or reentering data. She argued with one doctor whose concurrent access to the hospital's system blocked my nurse's access to my information. She called the hospital's pharmacy repeatedly to get my medications delivered. She met and called doctors several times. She even persuaded one doctor and a pharmacist to come to my room to resolve data errors in person. Despite these heroic efforts, I never received the correct medications during my stay. Indeed, my wife sneaked one of my inhalers into my room. After I used it, I finally began to recover.

A Near-Death Experience

At one point during my battle with illness and electronic health care data, the only asthma medication that had kept me alive began to wear off. I knew that if I did not receive the right dose within an hour or so, my condition would deteriorate rapidly and I would die. This critical information I had repeated nine times to doctors and nurses, who recorded it in my electronic health record. They promised that I would receive the medicine when it was time. That time came and went. My lungs began to scream with pain. My respiration rate accelerated. My breathing became more labored. I was crashing. I begged the doctor who next stopped in to check my condition for her help. She said she would authorize the prescription. The heroic ICU nurse stopped by my room, checked my electronic records, but could not find the prescription. She then ran to find a doctor to authorize my medicine. She succeeded. I received the medicine. I lived.

During the time I was hospitalized, I forced myself to remain coherent so that I could correct errors whenever medical professionals provided "prescribed medications" or came to run tests. Figure 1 illustrates my experience. I twice received food to which I was allergic, both times after a doctor "recorded" a list of my food allergies.

Needless to say, I was exhausted from labored breathing, a lung infection, pain, tests, effort expended to correct data model errors, energy wasted giving my medical history, and lack of sleep. Several times I stopped fighting. I relaxed. I thereby slowed respiration to my normal rate. This made my blood oxygen saturation rate drop precipitously, which in turn triggered monitor alarms—to which no one responded. (I learned later from a nurse's assistant that alarms always sound in the ER and the ICU, which is the reason no one pays attention to them.)

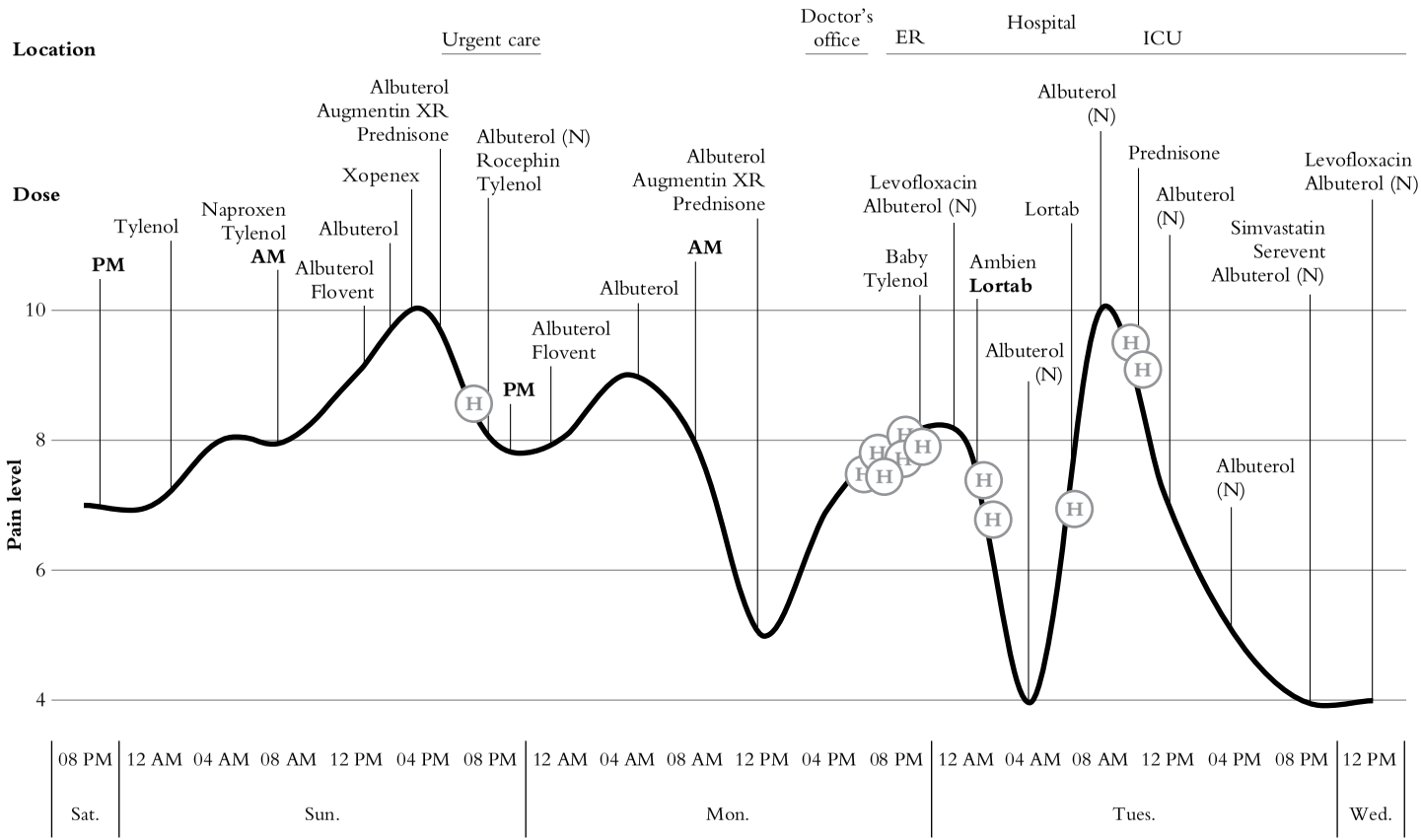

FIGURE 1. Asthma-pneumonia episode chronology. The chart shows the pain level, dosages of medication, and histories taken (H) for the author over five days by location. Daytime medications: Allegra, Nexium, Lisinopril, Omnaris, and Optivar. Nighttime medications: Simvastatin, Omnaris, and Optivar.

I finally understood the problem everyone was having when the heroic ICU nurse explained what she was doing while working with the hospital's electronic health records system. That in turn explained why so many caring, competent, knowledgeable, and talented medical professionals behaved so strangely when interacting with patients. It was because they were fighting a horrible data model. It was that data model that nearly killed me.

Electronic Health Information Systems

Medical personnel at urgent care and at the hospital who interacted with me all used a version of the same electronic health information system (the "system"). It became clear that everyone was fighting that system. Indeed, observations of their performance revealed that they wasted perhaps two fifths to three fifths of their time trying to make the system do something useful for them. The system prevented the medical professionals from fulfilling their duties rather than helping them.

Since my hospital stay, literature research and conversations with medical professionals around the world have confirmed that electronic health information systems are mostly broken. For example, I interviewed medical professionals, health care IT experts, and my allergist. They confirmed my sickbed analysis. Indeed, several experts said that they longed for handwritten charts once more hanging from the foot of every patient's bed.[4] My analysis argues for a less reactive response. The industry requires a careful analysis of the strengths, weaknesses, opportunities, and threats (SWOT) associated with building a national health information network. If the nation simply accepts the NHIN vision while health care IT vendors collect some of the $38 billion stimulus bounty, individuals and businesses will pay higher medical costs, patients will receive inferior care, and medical professionals will lose precious time fighting IT systems instead of delivering better care.

Killer Data Model

Poor data model design deters medical professionals from delivering quality care. Conceptual data models capture information requirements from medical practitioners' perspectives.[5] In contrast, IT professionals only vaguely understand medicine.[6]

There are three types of data models: conceptual, logical, and physical. Logical data models express information requirements from a technical design perspective (for example, schema for relational database management system [RDBMS], schema for extensible markup language [XML] documents, or

formats for health insurance claims [a message model]). Logical data models fail if conceptual models are wrong, if errors occur in the transformation of the conceptual model into the logical model (forward engineering), or if logical design is faulty.[7]

The root of the problem I experienced with health information systems is a bad data model. Evidence supporting my claim includes these observations:

- Incoherent database design isolates patient information from one department to the next and from one organization to the next. This wastes time and increases errors because medical personnel must enter patient information into a unique view of the system that corresponds to user identity and department. This prevents one medical professional from seeing patient information input by another medical professional.
- Patient information is easily lost inside the electronic records system.
- Hard copy patient information becomes dissociated from the electronic record.
- Neither the system design nor the data model in this case suited the health care professionals' work patterns. They spent considerably more time performing record searches and data reentry than they spent interacting with me, the patient.
- No master data management (MDM) was in evidence. Producing a consistent record of me as a patient required the ICU nurse to copy data from multiple database views into the inpatient record.
- Records of admitted inpatients are treated differently by the system than are records of outpatient or ER-only patients. No information about my medical history gathered during a prior visit to the same ER was available to my doctors or nurses.
- Nurses and doctors do not have ready access to formulary listings. As a result, they wasted much time searching for information about my daily medications. Access to lists of medications in the system is limited to those at the hospital pharmacy.
- No support existed for recording chronic allergies differently from allergies to ambient sources and foods. Lists of allergies were not available in drop-down menus, although these are well known to allergists and drug companies.

The root cause of these problems is the failure of IT system architects to capture (health care) business requirements correctly. There also is no evidence that anyone ever produced a reliable conceptual data model. The

problem occurs commonly. Too often, system architects simply gather lists of requirements, then they ask their favorite vendors to quote the price for a product. This is non-architecture and system non-design. Rarely do architects request information architecture.

Fault also rests with independent software vendors (ISVs) whose products fail to support the requirements of end users: real doctors, nurses, technicians, and pharmacists. Instead they build products to a marketer's or a developer's best guess about end users' requirements. It is easier to rush to market with a product that "looks good" to IT people but horrifies end users. This seems to have been the case with the electronic health information system used by the clinic and the hospital that treated me.

Another common problem is that useful conceptual data–modeling tools do not exist. This broad challenge to the industry makes the best data modelers' task more difficult as they work to create conceptual models, then validate those models with end users. Without good tools, information architects and data modelers often use technical elements to represent business concepts. This leads to problems with forward engineering because health care (business) concepts are mixed with data design technology artifacts. One group, HL7, has been working to develop a health care data model.[8]

IT security professionals in the medical industry appear to be reluctant to deploy document authentication and encryption for users. Many commercial health information systems can produce Adobe Acrobat versions of doctors' reports. These reports could be authenticated through the use of Adobe technology and transmitted to another physician via email encryption programs. The patient might even certify such transmission of his or her information by using electronic systems. This simple practice might have enabled admitting doctors to see my allergist's memorandum in their in-box instead of requiring paper copies to pass from one person to the next until they become lost.

Clearly, the most serious problem is the lack of a consistent data model across departments and providers. This wastes time and increases errors.

Unreliable Information

Poorly articulated data models engender disbelief in system data among end users, who see data inconsistencies in competing entries about patients, their symptoms, their illnesses, and data entered by different physicians and nurses who cared for the patient. This problem was in ample evidence in the eleven full histories taken by every medical professional who checked my condition.

If externally generated information history is difficult to integrate, particularly if that information is not in the form used most frequently by medical professionals in the receiving organization, then there is a propensity to misplace that information. Witness the lost memorandum from my allergist. That document was misplaced shortly after its confirmed delivery to the ER. Its loss dramatically reduced the quality and effectiveness of my care.

Other problems arise when doctors can arbitrarily block nurses or other doctors from completing data entry tasks. Such issues delayed provision of medications appropriate to treating my ailment (such as pain relief medication). Because information was not shared between departments or between the hospital and the clinic, each doctor felt obliged to build a diagnosis, and each nurse had to gather my data anew.

Bad Systems

Clearly, the networked monitors with alarms sounding so frequently that no one believes they mean anything is a serious design problem. Operating inconsistencies among systems and apparatus that increase the rate of false alarms lead to errors in patient care management, some of which are potentially fatal.

IT does provide an event-driven messaging technology to deliver data and manage workflow for doctors and nurses who need to review patient and treatment information. Too much of health care professionals' time is lost in tracing test results and gathering information about medications. These unnecessary activities dramatically increase error rates that lower the quality of patients' care.

Recommendations

A national health information network, while a laudable vision, requires massive data integration engineering at a scale never before undertaken by the IT industry.[9]

The only way to achieve the vision of reliable information transfer requires narrowing the scope of work to demonstrable and doable tasks that can be executed in a finite amount of time. NHIN proponents should not be fooled by IT vendors telling (false) tales of magnificent data exchange capabilities possible with their heath information system development. Instead, those proponents should call upon the best system and data architects to report for duty. Send these people to meet with doctors, nurses, test technicians, pharmacists, and hospital and clinic administrators. Have them learn what practicing medicine really means. Tell them to do these things:

- Build a business (medical information system) requirements model.
- Create a conceptual data model and information architecture.
- Validate these models in a public forum, as HL7 does, those used by open standards organizations such as OASIS, Object Management Group (OMG), Worldwide Web Consortium (W3C), and others.
- After the models are validated, create formal requests for information (RFIs) for vendors.
- Heath information technology vendors can respond to the RFI so you can see whose system matches those requirements.
- Seek hospital and clinic volunteers to test the new systems.
- Find the best matches to requirements and submit to the winning vendors a request for proposal (RFP) to build and install the first systems at the volunteers' facilities.
- Narrow down the list of vendors and send them a request for a quote or proposal to decide who will win the initial integration trial between two medical institutions and between two departments in each of those institutions.
- Establish criteria for success and measure vendors' achievements relative to that target, not one of their making.
- Be sure the vendors work for the volunteers and not for the government. A health information system is needed that meets their unique requirements.
- Integrate the systems. Pay the winning vendors a bonus for early completion.

The National Health Information Network will remain a pipedream unless and until IT professionals learn how to build systems and data models that meet end users' requirements, that is, models useful to medical professionals. My experience with an urgent care clinic and a major hospital convinced me that in the United States, it will be a long time before there is a consistent data model capable of recording a patient's health information, let alone a data model capable of accurately and reliably transmitting that information from one health care institution to another. Much of the groundwork required to achieve the NHIN vision remains undone. The $38 billion–plus allocated by the American Recovery and Reinvestment Act for a health information network will be squandered by IT vendors and hospital administrators long before the nation has a viable network unless the industry acts rationally to establish a program of development that is free of vendor and administrative greed. Take it from a person who found breathing quite difficult, and who nearly died because of a failed data model: Do not hold your breath waiting for a national health information network to appear.

Epilogue

Nearly one year after I posted a version of this article on my personal blog, the health care system continued to be plagued by data inefficiencies and inaccuracies because of insufficient priority being placed on building standard data models. For example, on a visit around that time to her primary care provider, my wife had some X rays taken. Another provider at a different location needed to access those X rays, but because of the lack of a coherent, shared (physical) data model, her X-ray image formats were not readable outside the system that created them. This incompatibility delayed moving forward with the treatment plan prescribed by her physician, and its solution required a second costly examination procedure that would generate serviceable images.

Dozens of health care and IT professionals have commented on my original blog post, both to validate and to express shared concerns about the realities of failed health information systems. Although disagreements were voiced, they related to medical issues associated with my treatment and not my data analysis.

Research I performed since writing of my travails revealed similar problems extant for all national health information networks, both planned and under construction. The root cause of interoperability problems for a national health information network is inadequate or nonexistent data models. Fortunately, data-modeling problems, while difficult, are solvable. For example, data-modeling work could proceed for a single medical subspecialty with limited scope for data transmission requirements. This is a narrower objective than promising to build a national health information network, and a substantial effort by experts at data standards bodies to create a narrowly defined model is feasible.

I hope that articles like this one and others in this book will help health care leaders learn the value of addressing systemic data-modeling issues like those that affected my care. Data-modeling improvements will prevent problems like those I experienced from becoming more commonplace.