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My Mother And The Medical Care Ad-Hoc-Racy

The former head of Kaiser Permanente finds that the health care system doesn’t work as well as it could, for his mother or anyone else.

by David M. Lawrence

It was a phone call children dread. “Mom’s fallen,” said my sister. “She’s in the emergency room at the hospital with a badly broken left leg. Her left shoulder and wrist are broken, too.” My mother is an eighty-eight-year-old mentally alert widow who is fiercely independent and lives alone in an eldercare complex. She had tripped and fallen hard while leaving a “Friends of the Columbia River Gorge” evening meeting at a colleague’s home in Portland, Oregon. She waited thirty minutes for the ambulance and several hours in the emergency room before she was admitted for surgical repair of her leg. After a two-hour operation to knit together the three fragments of her femur just below the hip joint, she remained in the hospital three and a half days. She was then transferred to a private skilled nursing facility (SNF) to receive the intensive physical therapy that would enable her to resume her busy life.

A Complex Web Of Care

In the first month of her combined hospital and nursing home stay, Mom was cared for by ten physicians: three primary care physicians, an emergency room doctor, two radiologists, an orthopedic surgeon, an anesthesiologist, a geriatrician at the SNF, and a wound care specialist. She was attended by at least fifty different nurses, ten physical and occupational therapists, and a host of nurse aides. Four nurses and two social workers arranged her transfer from the hospital to the SNF; two more arranged her stay in the assisted living section of her eldercare complex. At the SNF the nurse aides who bathed her, helped her with her toilet, and answered her questions were from Ethiopia, Eritrea, El Salvador, Brazil, Cambodia, and Vietnam. Mom had a hard time communicating with this array of non–native English speakers.

The hospital has a computerized medical records system for inpatient care, but records had to be printed out and hand-carried to the SNF. Because she’d been

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given blood thinners to prevent clots after surgery, at the SNF Mom bled from an unhealed surgical wound on her right foot each time she tried to do physical therapy. Her dermatologist had removed a cancerous growth at the wound site several months earlier. He was on vacation, though, and his records were inaccessible. Eventually Mom was transported by ambulance across the city to a wound care clinic. The specialist there discovered that the treatment regimen prescribed by her dermatologist was out-of-date and had retarded the healing process. By the time proper treatment began, she’d suffered several months of unnecessary aggravation and lost more than a week of physical therapy at a critical time in her recovery process.

As a result, entirely counter to her usual optimistic nature, she’d also developed frustration and cynicism about the health care system. Mom usually gives the benefit of the doubt to those around her. She was, in fact, happy with her individual providers and felt that, with a few exceptions, her personal needs were well met. What upset her were the mixed signals, the delays, the unexplained changes in treatment plans and prognosis, and the uncertainty about when she could leave the SNF to return to her eldercare facility.

Now, five months after the accident, Mom has moved back to her apartment. She gets around with a walker, does regular physical therapy, but still has the open wound on her foot that requires daily care. Her spirits are good, and she continues to actively participate in the lives of her friends and large family. But the care process was bumpy and poorly organized; the chances for medical error were great; and the costs to our family, Mom’s caregivers, and her insurers were far higher than they needed to be.

Too Many Opportunities For Disaster

At times Mom’s care seemed like a pick-up soccer game in which the participants were playing together for the first time, didn’t know each other’s names, and wore earmuffs so they couldn’t hear one another. Her care seemed like an “ad-hoc-racy” that involved well-trained and well-intentioned people, state-of-the-art facilities, and remarkable technologies—but was not joined into a coherent whole for the benefit of her or her family. My mother ricocheted from place to place like a pinball. Each contact brought another bill, different advice, and increased risk that something could go wrong. In spite of my experience as the leader of a large integrated health care system, there was little I could do to control what happened to her.

The glitches were many. A part-time physical therapist insisted that Mom could walk on her one-week postsurgical leg, in spite of clear orders to the contrary from...
the orthopedic surgeon. An occupational therapist told Mom to undo her shoulder and wrist straps in order to “slip into a nice nightgown.” Luckily, Mom is mentally alert, irascible, and tough as nails. She quickly sent these caregivers scurrying to check the medical records for proper guidance. Nurses disagreed about how to give her heparin injections and openly criticized one another in Mom’s presence. Frequent disagreements among doctors about treatment choices caused her anxiety and confusion. Reflecting on the care process, I would offer suggestions for how the system could be improved for everyone, including my mother during her next medical event.

Ways To Do Better

MEDICINE TODAY, ESPECIALLY EMERGENCY, complex, and chronic care, involves large numbers of professionals. Just look at the number of caregivers helping Mom for an acute, relatively simple problem! Gone is the day when a single doctor could take care of us. Mom’s care would have been quite different had her caregivers acted in well-developed, tightly coordinated teams instead of as an ad-hoc collection of individual actors. Instead of multiple opinions about treatment, there would have been one; instead of delays and confusion about changes in treatment, there would have been a clear process for group meetings and decision making. Instead of conflicts among caregivers, there would have been agreement about the role each plays depending on competence, experience, and training. Instead of lost information or miscommunication, there would have been tools for continuous discussion and information sharing. Instead of dropped balls as Mom moved from one care site to the next, there would have been well-designed handoffs to ensure continuity.

Expecting caregivers to manage so many different approaches is a recipe for disaster: There’s too much to remember and too many differences to accommodate. Each professional caring for Mom had his or her own way of doing things. The dermatologist and the wound care specialist approached the treatment of her foot wound differently. The primary care physician strapped Mom’s wrist and shoulder; the orthopedist thought this was overkill. The primary care physician prescribed blood thinners, inhibiting the ability of the physical therapists to provide the therapy Mom required to speed her recovery.
The “gold standard” that obviates these problems is evidence-based care, meaning care that is based on the best medical science now available. The process of deciding what the evidence supports is far from simple; professionals will disagree, the evidence is not always compelling, and judgments must be made to set the acceptable range of choices that the evidence supports. But the rewards of doing so—greater coherence in care and the chance to simplify an overwhelmingly complex process—are worthwhile. Evidence-based medicine is the only route to reducing medical errors and providing consistently better, more responsive care.

**Some Easily Made Improvements**

Sometimes fairly simple changes to the system can be just as important as the more complicated ones. Mom’s social and educational supports and her ability to manage her own care have been as critical to her recovery as the medical care she received. Yet the system provided precious little help beyond the medical component of her care. Had her treatment plan included medical, social, and educational interventions and been carefully designed to help her and us manage her care, we would not have been forced to address these needs on our own. Her recovery would have been expedited and her independence bolstered. Understanding Mom’s medical treatment and prognosis has been difficult enough. Understanding how to make her apartment safer, manage her reduced independence, and ensure that her ongoing self-care is appropriate has been more challenging still. We’ve been on our own for the most part, making it up as we go. Here and there people have provided names or contacts. But we’ve mainly relied on friends, eldercare community contacts, and trial and error. In this, my mother is lucky: Not all patients have the wherewithal, including the family advocates, to do this.

Another comparatively simple, logical improvement to the system that would bring large payoffs would be to automate clinical records. Providers noted critical information about Mom by hand; her paper records were hand-carried by couriers among health care facilities. The large number of caregivers involved in Mom’s care, the range of problems faced in returning her to a full life, and the quantity of information to manage in the process underscored for me the limits of traditional information management. The costs and dangers of relying on paper records, informal face-to-face information sharing, phone, and faxes are unacceptably high.

Finally, maybe this is a harder problem to fix, but while careening from caregiver to caregiver and site to site, we felt that no one but us could see the whole process of Mom’s problem unfolding. An organization needs to design and manage
the care process from start to finish. The individual elements of care that my mother received were generally satisfactory, but the pieces didn't fit together very well. The weak integration across providers and sites produced most of the confusion, delays, dead ends, and higher costs that we experienced. From our perspective, it didn't matter who gave the care or where it was given, so we had difficulty understanding why the left hand didn't know what the right was doing, why information generated in one part of the system wasn't available to another part; and why recommendations differed from stop to stop. The stress generated by this situation was significant for all of us, especially Mom.

We are grateful for the care Mom received; with the exception of the wound care recommended by her dermatologist, the quality and compassion of her individual caregivers were exemplary. But her care could have been far better for everyone involved. If we could implement some of the changes above, we could accelerate the slow, painful process of transforming a technically sophisticated but poorly organized and wasteful system to one that can bring the remarkable capabilities of modern medicine to patients. If care had been given this way to Mom, she probably would have recovered faster and had more confidence in her caregivers and in her ability to help herself. Her care would have been less expensive for Medicare, her Medigap insurer, and our family. Most important, we all could have focused more on helping Mom return to her active life than on dealing with the problems created by the care system itself.

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