Dismantling Rube Goldberg: Cutting Through Chaos to Achieve Coordinated Care

Hoangmai H. Pham, MD, MPH | Center for Studying Health System Change, Washington, DC.

Dr. Pham, a practicing general internist and health policy researcher, recalls her experience, as a granddaughter, of how patients, families, and physicians are often complicit in foiling the good coordination of care. **Journal of Hospital Medicine** 2009;4:259–260. © 2009 Society of Hospital Medicine.

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I was 12 years old before I knew her actual name, *Le Thi Canh*, because we always called her *Ba ngoai*. She was my grandmother, and this is the story of how she died.

To see my grandmother for the warrior woman that she was to me, you have to know that her farmer father sent her to the city for schooling because he didn't know what else to do with a daughter who was so smart. In early 20th-century Vietnam, this was an unusual thing to do with a girl. She met my grandfather there, when he was a campus activist, helping him hand out nationalist leaflets. He introduced her to his Communist friends. After the French jailed my grandfather, my grandmother courted him by sending him long letters and care packages while he was in prison. When he was finally released, they married and started a family while he struggled financially as a newspaper publisher and at other odd jobs. But in 1947 his own Communist comrades killed him as part of a party purge. He had been forewarned, and opted to go quietly rather than try to escape because he was promised that this would guarantee her safety. Before they killed him, somewhere in the mountains, my grandfather gave a soldier friend a poem he wrote for his wife. When she told me this story 8 years ago, more than half a century later, she recited his love missive from memory.

At the time of her husband's death, my grandmother had 6 children, the last born just a few weeks before. After a few years of scraping by (she ran her own one-room school for a while), she decided to leave Hanoi, and migrated south to Saigon with her brood. She was a famously strict parent, to hear my aunts and uncles tell it. She watched them like a hawk, worked full-time, put them all through school, and eventually rose to a leadership position in the Ministry of Social Work in South Vietnam. My memories of Saigon life are punctuated by scenes of siblings and cousins running around at her regal house, yellow stucco with porticos and black iron gates, at a corner turn in the road, past a cemetery.

On this side of the world, to see her, you would never have thought that my grandmother had led such an epic life. She never worked again after immigrating with us in 1975. She lived on Social Security checks, gardened, said Buddhist prayers, and was nanny to her grandchildren. She watched soap operas religiously, and could report their full plot lines while sitting and knitting. She bundled her many sadnesses in a contented, 4-foot 9-inch frame.

Having no home of her own, she would move from one child's house to another every few months so as not to wear out her welcome. But her children lived in Pennsylvania, New Jersey, Florida, Texas, and Maryland. And in most of these cities, she had a different primary care physician. She has 21 grandchildren; 8 of us are physicians. Yet the aunts and uncles told us very little about her medical care. She preferred older-generation Vietnamese physicians and I'm not sure that they were all competent, but her children did not want to argue with an octogenarian war survivor, and we deferred to their judgment. So we would find out only incidentally, for example, that a doctor prescribed her "tuberculosis drugs" for a visit to Vietnam.

For many years, *Ba ngoai* had no major medical problems. She was hypothyroid and hypertensive but on medication and generally high functioning. She had a lumpectomy for early-stage breast cancer. Then, a year or so after she told me the story of my grandfather's death, Alzheimer's set in. It became harder for her to report symptoms reliably, and she became mildly depressed. Her grandchildren were now birthing our own babies, and we offered these as a distraction, trying to surround her with celebrations of these new fruits of her life labors.

Ba ngoai's decline worsened 3 years ago. She became more easily fatigued, depressed, and confused. A few months before she died, she started to get dyspneic, and couldn't go for short walks any more. In retrospect, I think that her prescription for thyroid replacement somehow fell through the cracks, probably in the transfer of care from one city to another, although there remains a great deal of confusion in the family about exactly what happened. Her thyroxine levels dwindled. One evening in October of that year, at my uncle's house in Maryland, she became severely short of breath and nearly unconscious. They called her Maryland PCP, who sent her to an emergency room at a local hospital. She was admitted in severe congestive heart failure. When the hospitalist spoke with my mother and

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uncle, he explained that he could take some fluid off her lungs, but that she might need to be intubated and admitted to intensive care. Looking back, I guessed that she probably needed pressors and invasive monitoring. He asked them, "Is this what you want?" My uncle said, "No, it's not." And the hospitalist and the huddle of relatives decided she should come home.

The question was, into whose care would she be discharged? My elders were wary of contacting her PCP, partly because some blamed him for not catching and addressing her symptoms sooner, partly because to even confront him with this perception would cause him, and hence them, to lose face. This seemed too excruciating a scenario to them.

So at last, my uncle called my brother, the oldest grandchild and a very talented clinician. My brother is a pulmonologist, the kind of physician who once did a history and physical on a patient complaining only of "Really feeling bad, Doc," and confidently started a steroid infusion before returning the next day with test results confirming his suspicion of Wegener's granulomatosis. He took my grandmother's physical by phone, and told my uncle to increase her furosemide dose. Then he said, "I'm on call, but I'll be down there tomorrow. Call everyone together." Most of my relatives were already in town; they had come at news of her decline. She became alert enough for a couple of days to see and recognize most of the faces around her, like so many markers on a long journey. And then she died, slipped away.

I find it hard to define good coordination of care. My instinct as a researcher is to list measurable elements, but the tools we currently have generate metrics that are either reductionist—such as how rapidly a physician returns a patient's call—or so global that they no longer seem actionable—such as patient satisfaction. But if such metrics set the goal in the distance, it seems useful to also define its counterpart—*discoordination*—as a marker of the reality we would like to leave behind us as far as possible. Discoordination includes elements of discontinuity (lost patient history), fragmentation (actions by multiple players), overuse and/or inappropriate use of services, and ultimately, ineffective care (that is, the patient's needs go unmet).

My experience of discoordination was that of a Rube Goldberg contraption. It's composed of innumerable subtasks, each cleverly designed as the easiest solution to a seemingly short-term problem, as "quick fixes," but that in aggregate generate such chaos that the ultimate purpose is lost. They include acts of denial, lies to avoid embarrassment or conflict, and choices of convenience. My mother and her siblings accommodated my grandmother's choice of physicians by (secretly) not always adhering to care recommendations they didn't agree with, instead of challenging her. They took her to different physicians in different cities rather than risk embarrassing (due to an exaggerated sense of the smallness of the Vietnamese community) any one physician by dropping him. Her grandchildren, despite our medical training, found it culturally easier to defer to our elders than to intervene in substandard care. And none of her physicians aggressively followed up to ensure that a frail Alzheimer's patient was getting the care she needed. This is not to suggest that coordination is a simple task because Rube Goldberg machines make simple tasks complicated. Rather, it is a depiction of how indirectly we tend to address the problem.

I imagine a different course of events for my grandmother in the absence of discoordination. What if her children and physicians had understood and acknowledged to one another that her care was fragmented and therefore suboptimal? What if we grandchildren had confronted both *Ba Ngoai* and our parents sooner about their choice of physicians and offered to take on more of the burden of helping with her care decisions? Would we, as physicians, have been better able to ensure that her providers made rational clinical decisions? And what if she and her family had consistently recognized a single physician as her medical home? "Snowbirding" is hardly a rare phenomenon among Medicare patients; we could have designated one physician as primarily responsible for coordinating her care even without limiting her travel.

Care coordination is an inherently human activity. Supportive elements such as efficient transfer of medical information, resources for patient education and self-care, and adequate reimbursement can take us to the brink of, but not actually bridge, the chasm that we want to cross. Traversing that divide sometimes requires settling turf issues over undesirable responsibilities between different physicians and between physicians and other providers; clarifying who has primary responsibility for different types of decisions (I lead on cardiac issues and her son leads on health maintenance); and the violation of cultural norms of patients, families, and/or providers. These can be uncomfortable, unpleasant conversations that at times seem beside the point. But in aggregate, they *are* the work of coordination, because they force us to align our expectations of one another. No level of information technology could have dismantled the Rube Goldberg machine that trapped my grandmother. Her last of many lessons for me was that emotional courage, honesty, and perseverance offer a much more direct path through the muck.

Address for correspondence and reprint requests:
Hoangmai H. Pham, MD, MPH, Senior Health Researcher, Center for Studying Health System Change, 600 Maryland Avenue, SW, Suite 550, Washington, DC 20024; Telephone: 202-554-7571; Fax: 202-484-9258; E-mail: mpham@hschange.org Received 2 April 2008; revision received 26 May 2008; accepted 30 June 2008.

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