The Insiders as Outsiders: Professionals Caring for an Aging Parent

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Abstract

As professionals in geriatric medicine and social work, we are caregivers for our widowed mother of 90 years, a woman with neurocognitive disorder and multiple medical conditions. She has had repeated, problematic encounters with the health care system over the past 4 years. Caring successfully for an aging parent requires a comprehensive understanding of her unique medical, psychological, and functional status; need for social support; and overall goals of care. Poor communication between and among clinical teams—and with patients and families—is ubiquitous. The patient and family are not consistently listened to, or integrated, into the clinical team. We recount our experiences of one hospitalization and how we addressed the recurring obstacles we faced. Our training and experience gave us a firm understanding of the hazards of hospitalizing an elderly person and the need to be present, engaged, attentive, active, and vigilant. We caught and corrected major mistakes: failure to follow-up abnormal test results, multiple medication errors, undertreatment of pain, poor fall prevention, and inappropriate assessment and placement for rehabilitation. In a dysfunctional health care system, the family is, and must be, the ultimate fail-safe mechanism. We identify potentially effective solutions for the problems we encountered: adoption of dementia-sensitive and patient- and family-centered care, improved communication, better management of information (including better systems for monitoring lab results and for dispensing and reconciling medications), expediting care, changing reimbursement and regulation, and improving discharge planning and placement.

Keywords: Parent/child relationships, Dementia, Care coordination, Caregiving—informal, Hospital/ ambulatory care

As professionals in geriatric medicine and social work, we are caregivers for our widowed mother of 90 years, a woman with neurocognitive disorder and multiple medical conditions. She has had repeated, problematic encounters with the health care system over the past 4 years, with four hospitalizations, two operations, multiple emergency room (ER) visits, and stays in rehabilitation and home care. Caring successfully for an aging parent requires a comprehensive understanding of her unique medical, psychological, and functional status; need for social support; and overall goals of care. A good caregiver must serve as a vigilant advocate and source of clinical information in a fragmented, complicated system (Houle & Eckstrom, 2015; Kane & West, 2005; Kane & Ouellette, 2011). Poor communication between and among clinical teams—and with patients and families—is ubiquitous and results in many misunderstandings and errors, with potentially serious ramifications. In a system that should be patient-centered, the patient and family are not consistently listened to, or integrated, into the clinical team. This leads to problems in every setting of care: the clinic, ER, hospital, rehabilitation unit, and home. The literature abounds with evidence...
of potential hazards for patients: insufficient knowledge of the special needs of older persons, risk of falls and delirium, frequent medication errors, and insufficient coordination of care during transitions of care (Permpongkosol, 2011).

In this article, we will: (a) provide a brief sketch of our mother’s life, her current living situation, and our involvement in her care; (b) recount our experience of one hospitalization and how we addressed the recurring obstacles we faced; (c) analyze that experience in the context of the health care literature and some possible solutions to systemic problems; and (d) discuss how that experience has changed our attitudes and our professional practice. The scenario that we describe—things can and do go wrong—is all-too-common and has been told by caregivers before, but it should not be considered mundane or unremarkable, nor should it fail to cause shock and surprise. Serious problems persist, even when well-trained professionals like us are watching closely, and this is why this story is worth telling again.

Background: Mom’s Story
Mom, born in 1926, is a vibrant, intelligent, creative, and loving mother and friend. She grew up in Baltimore and earned an undergraduate degree in art and education. She met and married our father during his pediatric residency. They were constant companions for 63 years. Mom taught in the public schools, before becoming a homemaker and mother and assisting Dad with his medical practice. Mom was a masterful chef who loved to bake and prepare French cuisine. She created lovely floral arrangements and spent much time gardening. Dad was a caring, dedicated husband and father and a well-respected practitioner and medical school professor. Together they enjoyed listening to music and opera, attending art exhibits, reading the newspaper, discussing politics, playing cards, watching baseball, and traveling. Above all, they were devoted parents, who spoke to their daughter and son daily and shared holidays and vacations with them. Susan lived nearby and visited throughout the week. Robert lived in Florida and telephoned almost every day. Mom and Dad maintained their routines as they aged. Dad continued to work 20 hr a week into his 80s, and Mom stayed busy with her own activities. They were private, self-confident, and independent.

In late 2006, Susan noticed that Mom had become more difficult. She fiercely rejected any help. She became taciturn, and the situation worsened. She couldn’t do the laundry or go shopping unless accompanied. She required assistance with dressing and bathing. We had had an unsatisfactory experience with home health aides and decided to care for her ourselves. Susan retired early from her job in geriatric social work, and Robert worked during the day and assisted in the evenings and on weekends. Mom stayed in her home of 46 years, a familiar and comforting environment. We took charge of the finances, transportation, and household; coordinated her medical care; and assisted with personal care. We helped her to cope with a tremendous loss and to and live a full and meaningful life.

Life After Dad
Three years later, Mom has continued to function well, despite short-term memory loss and some impaired judgment. She is able to enjoy daily conversations with her children and shares her ideas and opinions on a range of subjects, including politics, sports, music, and the arts. We read to her daily from the newspaper, magazines, and books. We take her on frequent excursions to art museums, classical concerts, movies, and baseball games. She ambulates limited distances and climbs the steps with assistance at home but tires when walking for longer periods and requires a wheelchair in the community. She is still able to go out to her doctors’ appointments, as long as she is accompanied. We both share responsibility for her activities of daily living (ADLs); she requires assistance with dressing and bathing but is otherwise independent. She retains her sense of humor and values her connection to her children. She is a vital person who lives her life with enthusiasm and dignity.

The Caregivers’ Story
We are more fortunate than most families who are assisting aging parents. Our expertise is helpful in grappling with a complicated health care system and in serving as caregivers. We are both single and living in the same city, giving us the flexibility to focus our full attention on our mother. Mom is financially secure. She is covered by Medicare and supplemental insurance. She is followed regularly by a geriatrician, cardiologist, and a pharmacist (for anticoagulation), all who know her well. She, like other members of her generation, is part of the tremendous demographic wave of aging Americans, many with multiple chronic medical conditions, who count on their children for care and support. We as caregivers are typical of those described in the 2015 national caregiver survey of the AARP and National Alliance for Caregiving. We are part of the group of 34.2
A million unpaid caregivers in the United States who are caring for an older adult over 50 years of age. We are middle-aged adults living with and caring for an aging parent with complex conditions and performing multiple tasks, including assisting with ADLs and instrumental ADLs (IADLs), serving as advocates and coordinating care (AARP Public Policy Institute & National Alliance for Caregiving, 2015). We also represent a dwindling supply of caregivers in our country. The number of middle-aged caregivers in the United States is decreasing at the same time that the population more than 80 years is increasing very rapidly. This will adversely affect the number of caregivers per person for those more than 80 years, declining from 7.2 to 6.1 from 2010 to 2020, and even more over the ensuing decade, from 6.1 to 4.1 from 2020–2030 (Stone, 2015).

Susan has spent 30 years in social work, the last 7 years in a day care program for seniors. Most participants are on fixed incomes and have neurocognitive disorders, disabilities, and complex medical problems. Their family caregivers work full-time while caring for a parent or grandparent. Susan understands the fundamental need to empathize with each client and to use her knowledge of the health care system to seek and obtain the support they require to succeed. Her daily work has placed her squarely in the role of advocating for those she has served.

Robert, a geriatrician and home care physician, has been a doctor for two and half decades. He has broad knowledge of the clinical, psychological, social, and functional problems of older patients; the utility and danger of prescribing and administering medications; the power of the hospital to cure and to cause harm; effective interdisciplinary collaboration; and organizing and providing safe-care in the home to promote “aging in place.”

Like all geriatric professionals, we see the whole patient and focus on the family unit. We have certain expectations for our mother’s care: that those caring for her treat her with respect and dignity, master her medical history, and know her as an individual. They should be able to answer certain basic questions. What kind of person is she? What kind of life has she led? What does she like to do? What is she able to do? What is her day-to-day life like? What kind of relationship does she have with her son and daughter?

Given our backgrounds, we thought we fully understood the challenges of using the medical system, but we were still not sufficiently prepared for how difficult it would be to coordinate Mom’s care, prevent adverse consequences, and protect her from harm.

Case Summary: One Family’s View of A Challenging Hospitalization

Emergency Department

Mom’s admission to the hospital occurred because of a serious mistake.

We became very concerned when Mom failed to improve after receiving antibiotics in the Emergency Department for a lower respiratory infection. Her energy level remained low, she was less engaged, her appetite was poor, and her spirits were low.

We took her back to the ER at a local community hospital (her third visit within 10 days), after Robert called and obtained a report of a positive urine culture from her most recent ER visit. Disturbingly, we had not received a follow-up call from the ER staff about those results. Mom had been diagnosed (incorrectly it turned out) with a pneumonia. She was taking a broad-spectrum antibiotic prescribed at her last ER visit. She had new symptoms of fever, abdominal pain, and low blood pressure.

She was triaged quickly and brought inside the ER right away for assessment. The notes from her previous visits and hospitalizations were easily available in the electronic record. The staff allowed us to be with her. She was immediately seen by a nurse who spoke with us. We reviewed her medication list, past medical history (dementia, atrial fibrillation, stroke, aortic stenosis, hypertension, osteoarthritis, osteoporosis, constipation, chronic abdominal pain, urinary incontinence, lactose intolerance, hearing loss, and breast, thyroid, palatal, and skin cancer), and baseline function (total dependence in IADLS and partial dependence in ADLs (transferring, bathing, and dressing)). The physician soon came and took a history from us and Mom. After examining her and checking her labs, electrocardiograph, and CT scan, he diagnosed her with pyelonephritis and urosepsis, prescribed a course of intravenous (IV) fluids and antibiotics, and recommended admission to the intensive care unit (ICU).

Multiple ER staff members made medication errors. Robert went over her medications with the nurses and physician. The electronic record generated errors for allergies (omitted) and for warfarin (incorrect dosage) and acetaminophen, lactase, docusate, senna, and simethicone (prescribed as needed instead of regularly scheduled). This malfunctioning software was well-known to the staff but had not been fixed, leaving the system prone to repeated, potentially dangerous errors. Robert discovered this when he reviewed the medications each time with the staff.

There were other serious problems. The room was chilly. Mom complained of feeling cold, unsurprisingly for an older patient with circulatory problems. The nurses promised to bring warm blankets, but this didn’t happen expeditiously. We placed our coats over her. The ER stretcher was uncomfortable, exacerbated her chronic back pain, and made her blood pressure worse. Her pain was not treated promptly, because the doctor had not yet seen her; acetaminophen had not been ordered. The automatic BP cuff caused her pain during inflation. We asked the staff to use a manual cuff, but the technician continued to use the automatic cuff that caused Mom additional pain. This caused unnecessary agitation and increased her blood pressure.

The nursing staff knew about Mom’s cognitive deficits but initially refused to allow either of us to accompany her to radiologic tests outside the ER. We objected, because we feared she might become disoriented, fearful, and not
understand why she needed testing. After asking again, and explaining our rationale, the staff reconsidered and agreed that we could accompany her.

Intensive Care Unit
The transfer from the ER to the ICU proceeded slowly and took several hours.

When Mom reached the ICU, Robert again reviewed the medication list with the clinical staff, and the errors in her medications reappeared, due to faulty computer software. It took time for her medicine to arrive from the pharmacy, which inappropriately delayed administration.

Mom continued to have back pain. She was unaccustomed to the hospital bed, which exacerbated her back symptoms. We reported her pain to the nurse and asked that she be evaluated by the physician and treated. These requests went unheeded. She didn’t receive additional pain medication overnight and didn’t sleep well. We also informed the nurses that the automatic BP cuff was painful for her; a manual cuff was requested but never came. The automatic cuff caused arm pain and resulted in higher BP measurements.

The staff allowed one of us to stay overnight with Mom. The room contained a large reclining chair. We stayed on alternate nights during her hospitalization, to monitor symptoms, assist with transferring and toileting, and prevent her from becoming delirious. On her first night in the ICU, she awakened every 15 min to urinate. She refused to use the bedpan. Susan helped her with toileting, since the staff was not always available to assist her.

Intermediate Care Unit
Mom was transferred to the Intermediate Care Unit the next day.

Shortly after her arrival, she developed rapid atrial fibrillation, which was noted on the cardiac monitor. She was treated with an IV beta-blocker and immediately responded. The on-call physician who saw her thought the tachycardia had been triggered by an infection. He was unaware that she had already been diagnosed and was being treated, and Robert informed him of this. The physician said the antibiotic was not on her list. Robert verified that the antibiotic had been omitted from her orders when she was transferred.

After several days, Mom developed severe knee pain. Susan noted knee swelling and informed the nursing staff, who had failed to observe (or confirm) these new symptoms and physical findings. Due to Susan’s persistence, the nurse looked at her knee and notified the physician, who then requested an orthopedic consult. The orthopedist did not evaluate her until the next day. By this time, Mom was in extreme pain, and the swelling had increased. The orthopedist made a clinical diagnosis of pseudogout, a crystal-induced acute inflammatory arthritis, and performed an arthrocentesis (knee tap). Joint fluid was sent for microscopy and culture. It took another day for laboratory confirmation of the diagnosis, when the orthopedist returned to inject her knee with a corticosteroid. Her pain quickly resolved.

After her transfer, Robert inquired about her International Normalized Ratio (INR) level. She was taking warfarin and an antibiotic. He was concerned that her INR might be above the therapeutic level, placing her at an increased risk for bleeding. The nurse informed him, unexpectedly, that the level was too low. (This was likely due to depletion of her gastrointestinal flora, caused by the antibiotic, which decreased the effectiveness of warfarin and lowered the INR.) Robert asked the nurse whether he could speak with the pharmacist managing her anticoagulation, so he could inform him that Mom had previously suffered a stroke when her INR was too low. The nurse contacted the physician, who then called the pharmacist. After some back and forth, Robert spoke with the pharmacist directly. He informed him that Mom had suffered a stroke the previous year when her INR had been too low (she had been seen in the ER at this same hospital); at that time, enoxaparin, a second anticoagulant, had been prescribed, while her warfarin was adjusted upward, and this had been effective. Unaware of this history, the pharmacist initially decided to adjust the warfarin without adding medication, but changed his mind after speaking with Robert and hearing his concerns; enoxaparin was immediately initiated.

Mom stabilized clinically and was placed on oral antibiotics. We met with the discharge planner about sending her for rehabilitation. We preferred her to be admitted to a hospital-based, acute rehabilitation unit. The physical therapist (PT) evaluated Mom in the early morning, before she was fully awake, and she did not perform well. The therapist determined that Mom was not a good candidate for hospital-based rehabilitation, due to her cognitive and functional deficits (an inaccurate determination, in our opinion), which she felt, made her less able to benefit from this type of intensive program. Subacute rehabilitation in an outside facility was instead recommended. The discharge process was overly hurried. A decision had to be made quickly based upon availability rather than suitability, a common conundrum families face (Kane, 2011). She recommended a newly renovated rehabilitation unit in the community that was not far from our home. We did not have time to tour the unit, but reluctantly agreed to the placement, for a projected 14-day stay.

Rehabilitation
Mom was transferred and admitted to the rehabilitation facility on a Friday afternoon.

Her medications were ordered, per the hospital discharge instructions, but her antibiotics weren’t delivered until the next day, even though she was being treated for a urinary infection. The admitting physician saw her the following morning. Unaccustomed to awakening early,
she was exhausted and not alert or interactive. With little knowledge of her abilities, the physician, a retired surgeon, doubted her ability to benefit from rehabilitation. He conducted a cursory exam and entered orders for visits by the occupational therapist, with only one session scheduled for the weekend. She was seen by one therapist on the weekend and another on Monday, rather than the same one throughout her stay. On Saturday, the PT session was 10 min long; she ambulated with a walker, with assistance, in the hallway and on the stairs. The session was cut short, because she was deconditioned and easily fatigued.

The facility was not properly designed for older patients. The room was poorly lit. The bed was small, uncomfortable, and not adjustable. There was no reclining chair for a family member to stay with her overnight, so one was requested. The intercom system was nonfunctioning. The call bell was operating normally, but staff members did not respond promptly. The clinical staff did not pay attention to her complaints, including her abdominal pain, although it was well-documented as an active problem. Mom was labeled as “spoiled” and “attention-seeking.” There were insufficient staff to assist with transferring and toileting, particularly at night, and we helped her.

Things weren’t going well, and we were very concerned. We decided to take her home after only 3 days. The environment was suboptimal. She was not being properly monitored or cared for. She was not receiving much rehabilitation and not improving physically and functionally. She was not sleeping or eating well. She was dispirited about being there and asked repeatedly to return home.

We met with the social worker to ask whether Mom could be discharged home under our supervision, with home physical and occupational therapy. The social worker was initially reluctant, but confirmed that the appropriate equipment was at home (including a walker, wheelchair, grab bars, tub bench, and handheld shower hose) and that we would provide 24/7 supervision. She agreed to the discharge, and we took Mom home. Her mood immediately brightened on her arrival. She easily walked up the steps to the kitchen with our assistance, sat down in a chair, smiled broadly, and asked for a cup of tea.

Robert recalled that a urine analysis and culture had been taken over the weekend at the rehabilitation facility. The staff had failed to contact us. Robert was instructed to contact the on-call physician for Mom’s primary care geriatrician, so he could call the lab for the result; the tests were positive for infection, and Mom required another course of antibiotics.

Home Care

Because of our decision to take Mom out of the rehabilitation facility, we had to arrange for Medicare home care services through her geriatrician, who made the referral. Services started 1 week later, when she received her initial nursing, occupational and physical therapy assessments and began treatment. Over the next 3 weeks she convalesced and made steady progress. She was happy, engaged, eating well, and able to sleep without interruption in her own bedroom.

Discussion

Notable Problems

This perilous episode had a good ending. Mom recovered from the infection and returned home safely, where she regained her strength and sense of well-being. This good outcome happened only because we were with her throughout. Our training and experience gave us a firm understanding of the hazards of hospitalizing an elderly person. We knew how to keep her from harm: by always being present, engaged, attentive, and active. We kept her from becoming delirious and from falling. We caught and corrected major mistakes: ignoring of reported symptoms, failing to follow-up abnormal urine cultures, multiple medication errors (including omitting critical antibiotics), a subtherapeutic INR, inadequately addressing and treating pain, poor fall prevention, and inappropriate assessment and placement for rehabilitation. As her unrelenting, ever-vigilant advocates, we were able to protect her from adverse consequences.

Solutions: What the Literature Tells Us

There are potentially effective solutions for the problems we encountered: adoption of dementia-sensitive and patient- and family-centered care (with proper alignment of priorities of all concerned), improved communication, better management of information (including better systems for monitoring lab results and for dispensing and reconciling medications), expediting care, changing reimbursement and regulation, and improving discharge planning and placement.

Improving Geriatric Training for Health Care Professionals

Clinical personnel should be better trained to care of older patients (Institute of Medicine, 2008), including those with cognitive impairment, and to provide patient- and family-centered care, defined by the Institute for Patient- and Family-Centered Care as “an approach to the planning, delivery, and evaluation of health care that is grounded in mutually beneficial partnerships among health care providers, patients, and families.” (Feinberg, 2012; Institute for Patient- and Family-Centered Care, 2010). Provision of “dementia-sensitive” care should be the norm, not a rarity or exception (Callahan et al., 2006; Chodosh et al., 2012; Connor, Siebens, & Chodosh, 2015; Vickrey et al., 2006); this specific type of care considers the range of the patient’s abilities and potential; it accurately assesses what he or she can do, along with the essential support of...
family caregivers. Best practice models for family-centered care have been developed and studied, but their efficacy has not been sufficiently validated (Wolff & Jacobs, 2015). Geriatricians and other expert professionals can and should be enlisted to provide education for members of all health care teams on how to provide such care. The professions of family medicine, geriatrics, palliative medicine, social work, mental health, and nursing have long emphasized collaboration with the family in decision-making and in clinical interventions (Wolff & Jacobs, 2015).

Engaging and Collaborating With Caregivers From Hospital to Home

At each stage of hospitalization, clinicians should collaborate with family caregivers, rely upon them for critical information, and welcome them as part of the team. Caregivers should be included in the decision-making process and in formulating, revising, and implementing the plan of care. Information regarding medication changes, laboratory studies, and procedures should be shared promptly, and their implications fully discussed. Clinicians should perform comprehensive assessments of caregivers—their involvement, skills, deficits, and resources—and provide education in managing the medical, social, and emotional needs of the patient, and this should occur at the time of admission to the hospital and should be a standard of care for all facilities. For those families with limited resources or expertise to do effective caregiving, it would be essential to identify the assistance the patient will need to succeed after discharge.

Such processes have already been successfully put in place in four hospitals in integrated health systems in Utah, Texas, Iowa, and Missouri, as a part of quality improvement efforts to reduce readmissions for high-risk patients: heart failure patients, older patients, and patients with complex medical and social needs. These efforts included engagement with patients and families from the beginning of hospitalization and connecting underinsured and uninsured patients with services in the community (Silow-Carroll, Edwards, & Lashbrook, 2011). Five hospital-to-home transitional care programs, Coleman-Care Transitions Intervention (CTI), Naylor-Transitional Care Model, Boost, RED, and Bridge, have been chosen by the Center for Medicare and Medicaid Services and the Administration for Community Living Aging and Disability, and cited by a 2012 Family Caregiver Alliance report, as effective evidence-based interventions that actively involve family caregivers in transitional care (Gibson, Kelly, & Kaplan, 2012).

Self-management tools could also be used. The Ottawa Decision Support Framework is one tool that can help patients and families with decision-making and self-management (Ottawa Hospital Research Institute, 2014). Family caregivers should be informed about online communities that could provide additional advice and support (Nikzad-Terhune, Anderson, & La Bey, 2015).

Optimizing Management of Information

Better systems for managing information and preventing mistakes are needed. Accessing personal health records (PHR), such as the VA's My HealthE Vet and Epic's PHR application, can assist in the accurate transfer of patient information on admission to the hospital and can be updated at discharge (Demeris, 2015). The Siebens Domain Management Model (SDDM) and the Siebens Health Care Notebook, a self-management health care notebook, are tools specifically designed for managing information of dementia patients (Connor et al., 2015; Siebens 2008, 2011). SDDM classifies information into four domains: medical/surgical, mental status/emotions/coping, physical function, and living environment (Siebens, 2011). Coleman has emphasized the use of a Personal Health Record in the CTI (Coleman, Parry, Chalmers, & Min, 2006).

Hospitals require medication reconciliation during hospitalization—on admission, during transfers, and on discharge. Redundant procedures for verifying medications may still be necessary, particularly since computer systems generate unwanted errors and people make mistakes; a manual checkoff of medications by health care personnel, as patients move from one care setting to another, might be one simple, practical approach that could be undertaken. Pending tests at discharge should be electronically flagged to more than one person, to provide redundancy and assure proper follow-up by clinical personnel.

Expediting Assessments and the Delivery of Care

A patient's pain should be addressed and treated immediately, and this should be the highest priority. Despite numerous pain treatment initiatives throughout the U.S. health care system, and the designation of pain as the “fifth vital sign,” we noted firsthand that pain still receives insufficient attention. Consultations should be expedited, and medications filled promptly, with “stat” orders if indicated, and pain consultations should be available 24 hr a day.

Discharge medications for patients going to rehabilitation should be transmitted to the outside pharmacy and immediately filled, so that they are available upon the patient's arrival. In an era in which Medicare Part D has been fully implemented, the process of providing discharge medications can be efficient and seamless.

Changing Reimbursement and Regulation

The health care system does not provide financial incentives for clinicians to consult with family caregivers. Insurers and Medicare pay for acute medical care for a specific diagnosis, and caregivers are not included in that financial framework (American Geriatrics Society Expert Panel on the Care of Adults with Multimorbidity, 2012; Institute of Medicine, 2008). Centers for Medicare and Medicaid Services (CMS) issued interpretive guidelines in 2013 about discharge planning for patients who cannot care for themselves; these call
for the identification of family caregivers who can assist them at home. Rhode Island and Oklahoma legally require caregiver assessments before patients leave the hospital, but there is no mechanism to pay for such assessments by health care professionals (Wolff & Jacobs, 2015; Reinhard & Feinberg, 2015). A mechanism is needed, and CMS should consider this. The Joint Commission (JC) has standards for the inclusion of caregivers in hospital care. Such standards do not receive enough emphasis during accreditation. The JC could indeed prioritize collaboration with family caregivers, if it chose to do so, as a prerequisite for accreditation; this would help promote patient- and family-centered care (Reinhard & Feinberg, 2015).

Improving Discharge Planning and Placement

Discharging a patient too quickly from the hospital may conflict with the desire of patients and families to choose an appropriate facility for rehabilitation (Kane, 2011). The rush to discharge leads to evaluating patients for rehabilitation according to the demands of the therapist’s schedule, without taking into consideration the time of day the patient may be at his or her best. There is insufficient data on how often inaccurate evaluations and placements occur. One retrospective study found that physical therapists’ recommendations for discharge locations and services, when implemented, resulted in fewer patient readmissions to the hospital (Smith, Fields, and Fernandez, 2010), but the imprecision of physical therapy assessments has been cited in one systematic review as a significant problem (New, 2009). Options for older patients with cognitive impairment are too limited. Regulations could stipulate that a minimum number of rooms be designated for this population in free-standing rehabilitation centers and that they meet certain requirements for staffing, design, and safety. Specific rehabilitation programs for dementia patients recovering from hip fracture do exist (Resnick et al., 2012); it is not unreasonable to suggest that it might be feasible to design such units for dementia patients requiring rehabilitation after hospitalization for other conditions.

Conclusion

What lessons have we learned, and what advice can we offer to others?

In a complex and dysfunctional health care system, we were the ultimate fail-safe mechanism. As we observed, too many things can go wrong for older persons, and in our case, we felt we had to be forceful advocates for our mother. Currently, family caregivers are not formally and consistently incorporated into the team from the time the patient arrives in the hospital until discharge. Given that situation, we made every effort to communicate regularly with clinical personnel and articulate our mother’s values, priorities, and needs. Tragically, many patients with dementia are stereotyped, undervalued, and underestimated by health care personnel—who lack sophistication and empathy—and by a health care system that does not give them a fair chance.

We realize there are many instances in which no family member may be available, or capable, of serving as an advocate, and in those instances, a geriatric case manager, advanced practice nurse, or transition coach could be appointed by the hospital to assume such a role throughout the patient’s hospitalization. There is much to be done to help family caregivers to access the training and help they need to be successful. Caregiver assessments should be made when the patient is admitted. For those with insufficient caregiving skills or for patients without family caregivers, a combination of federal, state, and community resources must be generous enough to fill that void and provide the care and support that individuals require. Our society needs to plan and make commitments for a future in which family caregivers are disappearing.

How has this experience changed us personally and professionally?

As caregivers caring for a vulnerable parent, we have become more wary, careful, and protective, supremely cognizant of the need to communicate clearly, provide essential information, express preferences, track progress, and participate in decisions. Although Susan has suspended her practice in order to care for Mom, her caregiving experience has nonetheless reaffirmed her contention that clients enrolled in medical day care, who are hospitalized, be offered support and direction by having the day care social worker connect, and collaborate with the inpatient team; this is beneficial to the client and family, by identifying the necessary resources for patients and families to succeed. As a physician in the practice of geriatrics and home care, this caregiving experience has also made Robert more proactive at the moment patients go to the ER and enter the hospital; he is speaking immediately with members of the health care team, discussing the patient’s clinical history, priorities, and social situation and maintaining regular communication. It has focused Robert’s educational efforts with trainees, with an emphasis on consistently optimizing care transitions, coordinating care meticulously, advocating for the patient and family, and assuring that caregivers have prompt follow-up and sufficient assistance to carry out their responsibilities safely and competently.

Ideally, the provider-centered acute care paradigm can and should evolve toward one that addresses the common priorities of patients and families; this would include the routine assessment of caregivers and enable them to acquire the self-management skills to be able to care for patients with complex, multiple conditions. The proper tools and processes of care to accomplish these goals exist now. They need only be universally disseminated and adopted. The Oklahoma CARES law identifies caregivers as crucial to good care, and this may encourage other states to follow suit. System-wide imperatives, mandated by Medicare, to reduce hospital readmissions, have led to more attention on caregiver engagement as a quality improvement and cost-saving strategy, and this also could have positive effects on the way care is structured. For those without caregivers, or with family members who are unable to be caregivers, the system needs to provide...
alternate means of support. If such a new emphasis leads to rigorous quality standards, changes in reimbursement, and an accreditation process that requires and enforces patient- and family-centered care, the system would be significantly strengthened and signify a positive, constructive shift toward the type of care all patients and families deserve. We hope these worthy goals will be achieved.

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