Learning From My “Lived Experience” With the Health Care System

By Elizabeth Galik, PhD, CRNP

A few months ago, I tripped on some steps while walking outside, fell, and sustained an open fracture of my right ankle. This accident required a brief hospital stay, surgical repair, and a prolonged period of no weight bearing and no driving. My surgery and rehabilitation have been going well, and I am making progress to a full recovery. I am fortunate to have lived 55 years and have this be my first emergency encounter with the health care system.

As I have reflected on this “lived experience” with the health care system, I imagined how my journey would have been different if I was 20 to 30 years older. It would have been more like the experiences of our post-acute care patients. I learned several important lessons about optimizing rehabilitation and recovery through my interactions with the acute and community-based health care system that are also applicable to our post-acute and long-term care setting. These include (1) setting realistic expectations of care and prognosis, (2) managing staff and patient anxiety related to fear of falls, and (3) supporting patient advocacy. We still have room for improvement in all three.

Realistic Expectations

I was fortunate to have worked with skilled practitioners who set realistic expectations related both to my prognosis and the care that I would receive. Prior to my surgery, the orthopedic surgeon set the stage for what I might encounter when I woke from anesthesia. The goal was to have an internal fixation of my fibula, but he prepared me for the possibility of an external fixation. Waking up from anesthesia with no external rods and pins was a huge relief, but if they had been needed, I would have been prepared.

After anesthesia care, the nurses explained the care routines I would experience, and the wonderful outpatient physical therapist worked with me to have realistic expectations regarding the timing of achieving my rehabilitation goals.

When patients come to post-acute settings from acute care, the patients and their families frequently assume that the staffing levels and availability of the interdisciplinary team in post-acute care will be like what they experienced in the hospital setting. Even when we are providing quality care, when the care doesn’t meet unspoken expectations, conflict often arises. Setting realistic expectations at the time of admission about the differences between skilled care and acute care practices, the availability of different members of the interdisciplinary team, and the prognosis and potential complications may help to avoid misunderstandings and dissatisfaction with care.

A recent integrative review about family needs and expectations in nursing homes highlighted that families want to understand as much as possible about the patient’s condition, the care delivered, and changes in the treatment plan (Med Care Res Rev 2021;78:311–325). When this information is proactively provided by the interdisciplinary team, it promotes greater trust, acceptance, and satisfaction.

Fear of Falls

Although I appreciate that an accidental fall had resulted in my fracture and hospital stay, I was surprised by how fearful the staff was about me falling again in the hospital. Only one nurse allowed me out of bed before my discharge. I tried advocating for myself and shared that I still had one uninjured leg, a strong upper body, and had used a minimal amount of pain medication; I also was a nurse practitioner whose research and clinical practice focused on optimizing function and physical activity among frail older adults. After a lot of convincing, I was eventually permitted to transfer to use a bedside commode. Four nurses entered the room prepared to catch me and appeared shocked with how smoothly it went.

Embracing Patient Advocacy

My hospital admission occurred while COVID-19 rates were beginning to spike, so no visitors or family support individuals were allowed to enter. Given my background in health care, I was able to be an effective self-advocate during my hospitalization and recovery. I also had a wonderful support network that was available if needed.

Very few of our patients in the PALTC setting can effectively advocate for themselves. An engaged family member or friend who knows the patient well and is available to advocate for their loved one serves as another line of defense against potential adverse outcomes.

Additionally, if the patient is in our facility for a post-acute stay, we need to prepare the patient and family member for an eventual transition back to a home-based setting. This can only occur when we truly embrace and support patient advocacy and learn to partner with the patients and their advocates.

We sometimes don’t like to hear the concerns or questions from the patient advocates, but they play a critical role in the recovery of the patient.

New Parkinson’s Disease Pocket Guide: A Helpful Assistant for Busy Practitioners

By Joanne Kaldy

Despite Medicare data showing that about 25% of people with Parkinson’s disease (PD) reside in nursing homes, many practitioners may not have a lot of experience with diagnosing and managing this condition. As Nora Reznickova, MD, a geriatrician at Colorado Permanente Medical Group in Boulder, said, “Starting with the differential diagnosis, practitioners aren’t necessarily comfortable managing PD patients. They may not feel like they have the necessary skills and experience, and they worry that they’ll miss more atypical Parkinsonian disorders.” Dr. Reznickova and others in AMDA – The Society for Post-Acute and Long-Term Care Medicine worked on a new PD pocket guide to help boost practitioners’ confidence in addressing this condition.

Essential to effective PD treatment are understanding all the manifestations of the disease; recognizing the importance of basic, competent primary nursing and medical care; understanding the roles of various disciplines, therapies, and specialties; and adopting the concept of realistic goal setting for each patient.

The pocket guide includes some tools to help with difficult issues related to PD, such as assessing not only motor symptoms but nonmotor ones which are frequently overlooked,” said Dr. Reznickova.

Dr. Galik is editor in chief of Caring for the Ages. The views the editor expresses are her own and not necessarily those of the Society or any other entity. Dr. Galik is a nurse practitioner in LTC- and community-based settings through a clinical practice with Sheppard Pratt Health System. She is a professor at the University of Maryland School of Nursing, where she teaches in the Adult-Gerontology Primary Care Nurse Practitioner Program and conducts research to improve care practices for older adults with dementia and their caregivers in long-term care.
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2021;22:2212–2215). Gradual dose reduction meetings rarely if ever offer an adequate approach to systematic clinical reasoning and problem solving. Here are suggestions for a more valid approach:

• Identify and utilize some of the many reliable and helpful references on diagnosing and treating BPIs (J Am Med Dir Assoc 2017;18:284–289).

• Reinforce essential first steps in addressing behavior issues, including medical considerations (Michael B. First, DSM-5 Handbook of Differential Diagnosis, American Psychiatric Publishing, 2014).

• Remind everyone that behavior is not automatically a “psychiatric” issue requiring a consultation.

• Discuss with your facility the importance of not trying to game the system.

• Focus everyone on clinically valid diagnoses, not on “allowable” diagnoses.

• Vigorously help create an environment that limits the panic and prescriptive urgency of staff and practitioners in cases of aggressive and disruptive behavior.

• Help your facility reassess and limit its use of consultants.

• Inform psychiatric consultants that they are not expected to load up on allowable medications; rather they should identify what they know and how they intend to help provide clinically appropriate care.

Furthermore, it is imperative to read and understand the regulations and surveyor guidance related to the use of psychotropic medications. Most medical practitioners and facilities have not done so or do not understand their implications. The current political, clinical, and regulatory approaches to the situation have led to serious unintended but predictable consequences, including the excessive and inappropriate use of antiepileptics. Telling people how they should or should not treat BPIs is an inadequate substitute for showing them how to think through these problems correctly. Fixing this messy situation to obtain optimal results demands a different approach all around.

Dr. Levenson has spent 42 years working as a PALTIC physician and medical director in Maryland. He has helped lead the drive for improved medical direction and nursing home care nationwide through his work in the educational, quality, and regulatory realms.

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“There is no cure, and that is difficult for people to hear. However, there are treatments that can significantly improve quality of life, and we can talk about those. For instance, I always encourage people to start exercising as intensively as they are capable.”

Communication with staff is another challenge the guide addresses. As David Smith, MD, CMD, president of Geriatric Consultants in Brownwood, TX, observed, “One of the greatest challenges for physicians (and advanced practice providers), from my own experience, is that nursing and CNA [certified nursing assistant] staff may not recognize condition changes caused by PD’s progression. Without this information, prescribers are often unable to make those earlier interventions.” To address this, the pocket guide includes an integral history that nursing and CNA staff can collaborate on before the prescriber comes to the facility.

There is an information overload right now, Dr. Smith observed; although COVID-19 demands top priority, that doesn’t mean everything else went on vacation. “We need to be increasingly efficient and find new ways to identify problems and fix them. That is a tall order, but we can’t put this off until after the pandemic,” he said. PD is one area that needs attention, and the new pocket guide can help. He said, “Parkinson’s can progress over time. There are issues that are urgent and will come to the forefront, such as PD-related psychosis, and these will need prompt action and attention.” However, it’s important to be able to identify subtle changes as well. “The pocket guide will give people the resources they need to identify and address those subtle changes, as well as the more obvious signs and symptoms,” Dr. Smith noted. He added, “The guide is like an auxiliary brain” for practitioners and their teams.

The pocket guide is available in a package with the Society’s clinical practice guideline (CPG) on Parkinson’s disease. For more information or to order, go to https://paltc.org/product-store/parkinsons-disease-cpg-parkinsons-disease-psychosis-pocket-guide. The CPG and pocket guide are available in both paper and digital versions.