PALLIATIVE PEARLS
BY ENCLARA PHARMACIA

Forest or Trees?
Overlooked Contributors to Troublesome Symptoms in Dementia Care
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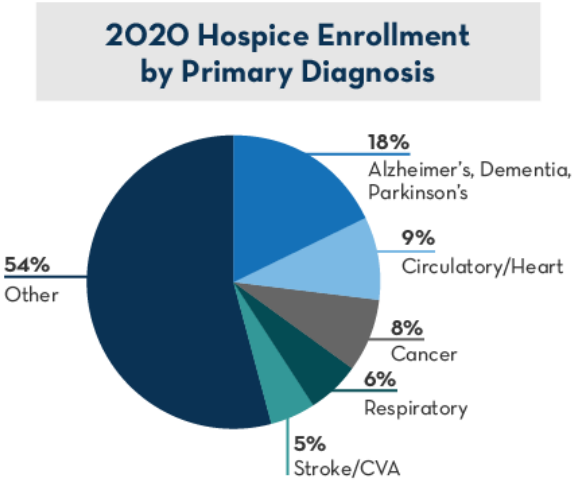
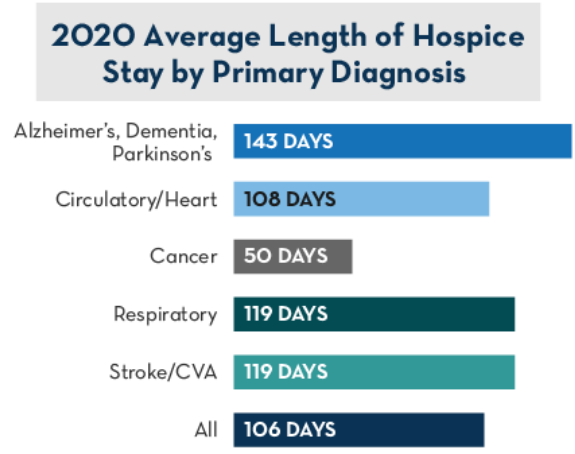
Enclara Senior Clinical Manager, Genoveva "Hennie" Garza, MS Pharm, RPh, has over two decades of experience building collaborative relationships with nurses, physicians and other health care providers to help improve the quality of life of seniors through better medication outcomes and processes. She is also a Clinical Assistant Professor of Pharmacy Practice-Geriatrics for the School of Pharmacy at Texas Tech University. In this clinical feature, Hennie discusses ways to improve comfort and dignity for patients living with dementia.





As a hospice pharmacist, one of the most frequent questions I encounter is how best to manage the behaviors and psychological symptoms of dementia (BPSD). That's not surprising. More than 90 percent of persons with dementia experience BPSD and about one in five hospice patients have a primary diagnosis of Alzheimer's, dementia or Parkinson's. That's more than cancer and heart disease combined. These patients also have the longest stays, averaging 143 days. Of course, we know many patients with another primary diagnosis may also experience some degree of dementia as well.

Given how much time people living with dementia spend in our care, we need to ask ourselves if we are providing care strategies that support the best possible quality of life. Doing so can be a challenge because BPSD can be both disruptive and difficult to treat. In this article, I hope to share some of my lessons learned and insights from collaborating with hospice nurses and physicians in getting our patients with BPSD to a more comfortable state.

When a patient presents with agitation, repetitive questioning, aggression, sleep problems, wandering and various inappropriate behaviors, frequently, the caregiver may request a medication to help calm the person or some other intervention to provide some relief. The prescriber's first impulse may be to start antipsychotic medication or a benzodiazepine. This is where I believe we may be missing the forest for the trees… or possibly the trees for the forest. While these behaviors are more common in people living with dementia, they may also have another underlying cause beyond that primary diagnosis.

Are Hospices Overlooking Pain in Dementia Patients?

When my nurse colleagues reach out for help with a dementia case, the patient is often already receiving one or more psychotropic or sedative drugs. I find it interesting that despite the volume of evidence proving the extemporaneously compounded gel combining lorazepam, diphenhydramine and haloperidol is not effective due to poor systemic absorption, I still see this combination ordered and used. Have we not stopped to consider that the current treatments are ineffective because there is another underlying reason for these troublesome behaviors? In my personal experience, many times I learn the person with the behavior problems has a diagnosis in which pain is a common symptom, but either the current pain medications prescribed are ineffective or the pain medications are PRN rather than scheduled and only to be given as needed. And occasionally, no pain medications are visible on the patient medication profile at all. Consider the person with dementia who also has diagnoses of osteoporosis, chronic back pain, osteoarthritis, or any other condition where you would expect or anticipate the person could experience pain, including infections. Without effective pain management, of course they're going to be agitated!

While it is important to consider delirium, untreated or undertreated pain should always be considered as a source of agitation or other behaviors in persons with dementia. The Pain Assessment in Advanced Dementia (PAINAD) scale is considered an effective screening tool for both verbal and non-verbal dementia patients. I learned from a wise geriatric psychiatrist that a good starting place is to schedule acetaminophen 500mg to 750mg three times daily routinely for seven days and then re-evaluate. Of course, other options are available and should be considered.

Unfortunately, one cannot always rely on patients with dementia to make their needs known without prompting. They may even deny pain symptoms when asked. In home settings, we can sometimes rely on family caregivers to identify pain and other symptom management needs for their loved ones because they spend so much time with them. Assessing pain in persons with dementia can be more difficult in institutions where different people are caring for the patient at different times, particularly if the staff is not trained to observe non-verbal signs of pain. That is just one of several challenges to treating dementia patients in these settings.

How Does Care Setting Impact Hospice Dementia Care?

It can be difficult to estimate the number of persons with dementia receiving hospice services who reside in skilled nursing facilities and/or assisted living facilities, but as of 2016 nearly one-third of all Medicare decedents who opted into the hospice benefit (regardless of primary diagnosis) passed away in a residential facility and over 40 percent of residents of nursing homes, assisted living facilities, and skilled nursing facilities are living with dementia. When a person receiving hospice services lives in a care facility, we know we will face challenges that sometimes have nothing to do with the disease state.

At the height of the COVID-19 pandemic, hospices faced limited access to patients in residential facilities and, while those restrictions have mostly abated, other challenges remain. Reduced staffing levels in facilities impacts care provided and administration of medications, especially PRN medications. Additionally, regulations may limit our selection of medications to use, specifically, antipsychotic medications. Antipsychotic medications carry an FDA boxed warning for increased morbidity and mortality in geriatric patients with dementia. Deaths from heart failure, infections (primarily pneumonia) and increased incidence of stroke and other cerebrovascular adverse events have been reported, but some hospice physicians still opt to use antipsychotics as perhaps the benefit outweighs the risks based on the patient's prognosis. This practice can lead to resistance at long-term care facilities because these providers can be subject to lower CMS star ratings if a higher proportion of their residents are prescribed these drugs, regardless of hospice enrollment. Patients in residential facilities may also experience greater exposure to polypharmacy, which can be particularly problematic for dementia patients.

Can Common Medications Worsen Some Dementia Symptoms?

Hospice "inherits" a plethora of medications used in persons with dementia and we are often adding new drugs for symptom management throughout a patient's hospice stay. This creates a risk for adverse drug events (ADEs) that can be mitigated by careful monitoring and pharmacist involvement. One important way to minimize risk is reducing the total number of drugs and/or doses a patient is prescribed through deprescribing. This may include certain dementia drugs, which are less helpful for advanced cases and may have troublesome side effects and potential for drug-drug interactions.

Antidepressants, particularly SSRIs, are often effective in managing BPSD (e.g., depression and apathy), but it is important to note that any medications that increase the availability of the neurotransmitters serotonin, norepinephrine, and dopamine may also cause or contribute to an agitated state. These include not only most antidepressants, but other medications commonly used in hospice, including opioid pain relievers and some medications for nausea. Symptoms of serotonin toxicity present on a spectrum from mild to life-threatening, and often emerge in the first 24 hours after starting a new drug, so it is especially important to monitor patients during any transitionary period. Please note that this adverse effect is neither limited to nor specific to persons with dementia and can affect other persons receiving hospice care.

Anticholinergic drugs (PDF) are also implicated in both the development of dementia and ongoing symptoms of BPSD, including confusion, difficulty concentrating, agitation and memory problems. Anticonvulsants, systemic corticosteroids, sedatives, and anti-Parkinsonian medicines all have some potential to worsen BPSD. Also consider antibiotics as contributors to delirium-like symptoms.

Consider Non-Pharmacological Interventions for BPSD in Hospice

Helping persons living with dementia requires us to take a step back to consider non-pharmacologic approaches. Think about the things that make you cranky in your day-to-day life and then imagine you aren't able to address or even articulate them. When I'm feeling stressed out and overwhelmed, it's often because I'm really hungry or thirsty. A quick snack or just a glass of juice can turn my afternoon around and the same is true for our patients. If sleep is an issue, we have pharmacological interventions for that, but we can also replace scratchy bed sheets or turn on a fan in a stuffy room. Regularly orienting patients to their environment and surrounding them with familiar objects can make them feel safe and less scared.

This is also an area in which complementary treatments such as a massage, music or aromatherapy may help. Indeed, one common element of many complementary treatments is human interaction. Particularly in institutional settings, loneliness and isolation can be a significant risk factor for BPSD, so this is also an area to engage volunteers and clergy when possible. On a related note, hearing loss is also an overlooked contributor to isolation and discomfort. In the past, the cost and need for audiology appointments and fittings were significant barriers to hearing aid access in hospice. However, the FDA authorization of over-the-counter hearing aids in 2022 has changed all that. These devices are now widely available for as little as $100.

Dementia is a Growing Challenge for Hospices

As hospice clinicians we care for the whole person, including disease management, physical, psychological, social, spiritual and practical needs. Serving them requires empathy, creativity and a willingness to try a variety of interventions. It is essential that we get it right because as the baby boomer population ages, the total number of people with dementia is likely to grow significantly, from 7 million Americans today to more than 9 million by 2030 and nearly 12 million by 2040.