As the year 2020 approaches, Alzheimer’s disease research is more generously funded and richly infused with biomarker studies and clinical trials addressing a diversity of therapeutic targets and approaches that move beyond anti-amyloid therapies — to tau, for instance, and to neuroinflammation and neurodegeneration — than it was a decade ago.

Although amyloid remains a common target of phase 2 and phase 3 disease-modification clinical trials for Alzheimer’s disease — which may still prove fruitful, according to several leaders in the field — the tide has turned toward earlier intervention.

“Almost all of the clinical trials using amyloid drugs have been in people who already have some level of cognitive decline,” in whom, it is now appreciated, the pathological process of Alzheimer’s disease has long been underway, said Keith N. Fargo, PhD, director of scientific programs and outreach for the Alzheimer’s Association. “Now, a major outstanding question is whether or not treatment with an anti-amyloid drug would be beneficial in people who don’t already have symptoms.”

Eyes are on the ongoing Anti-Amyloid Treatment in Asymptomatic Alzheimer’s Disease (A4) Studies and other trials that target tau and other factors linked to Alzheimer’s.

Reisa A. Sperling, MD, and other investigators continue to test therapies for Alzheimer’s disease that target the build-up of amyloid in the brain.

From Inhaled Insulin to Oral Bacteria: Ongoing Clinical Trials of Alzheimer’s Disease Biomarkers, Therapeutic Targets Show Promise

By Christine Kilgore

Team Sleuthing and Other Strategies for Problematic Pain in Cognitively Impaired Individuals

By Joanne Kaldy

Pain is a common and serious problem in the older population. Managing pain often is challenging, but it takes on an additional degree of difficulty when the person is cognitively impaired or has dementia. At the beginning of a session on Pain Management in the Cognitively Impaired at the 2019 Annual Conference of AMDA — The Society for Post-Acute and Long-Term Care Medicine, speaker Anthony Burgess, MD, MHA, asked how many audience members were confident about treating pain. Several hands went up. When he asked how many had that same confidence treating pain in patients with cognitive impairment or dementia, only a few people indicated that they did.

“It can be challenging,” Dr. Burgess admitted. “It’s great if these patients can talk to me, and I can have conversations with them about pain. But if I can’t talk with patients, I have to depend more on visuals regarding physical movements, facial expressions, and body language to determine how much pain the patient is feeling.”
facial expressions, and social changes, as well as insights from other sources.”

First, Some Facts
Why is this such an urgent issue? The numbers are startling. As Dr. Burgess noted, up to 83% of people over age 60 experience pain of some kind, and 75% of those over 65 have persistent pain. Over half of people with Alzheimer’s disease have pain, and up to 50% of older people with dementia experience persistent pain. Yet problems with pain are often missed, and pain is undertreated in about 21% of nursing home residents.

Targeting Troubles With or Without Talk
When it’s possible to communicate with the patient to some degree, assessments such as SOCRATES can help. This is an acronym used to gain insight into the patient’s feelings:
- Site: Where is the pain? Or the maximal site of the pain?
- Onset: When did the pain start, and was it sudden or gradual? (Include whether it is progressive or regressive.)
- Character: What is the pain like? An ache? Stabbing?
- Radiation: Does the pain radiate anywhere?
- Associations: Are any other signs or symptoms associated with the pain?
- Time course: Does the pain follow any pattern?
- Exacerbating/relieving factors: Does anything change the pain?
- Severity: How bad is the pain?

Playing Detective
When the patient is cognitively impaired, Dr. Burgess suggested, clinicians have to do a bit of detective work. They can look at the patient’s history for previous or ongoing problems or issues that might be causing pain, and they can ask family members and/or caregivers for any thoughts or insights.

Observing the patient, however, can be the most telling. For instance, some facial expressions may indicate pain. These include frowning, grimacing, wrinkled forehead, closed or tightened eyes, a distorted expression, rapid blinking, furrowed brow, tightened lips, or clenched teeth/jaw.

Body language and physical indicators also can be very illuminating. The signs of pain include a rigid body posture; fidgeting; increased pacing; mobility/gait changes; limping; rubbing body parts; clutching or holding bedding, pillows, or other items; or constant shifting or repositioning.

Even though people with cognitive impairment may not be able to tell you about their pain in words, they can still “vocalize” messages about their discomfort. Listen, Dr. Burgess said, for sighing, moaning, groaning, howling, screaming, grunting, chanting, calling out, noisy breathing, asking for help, crying, and gasping.

Scales: Tried and True
There are some validated scales that can help assess pain in older patients. The Verbal Numeric Scale (1–10) and the Verbal Descriptor Scale (words describing severity of pain) also are useful to help assess pain in patients who can still converse and answer questions. For those individuals who can no longer communicate verbally, the Visual Analog Scale and FACES Pain Rating Scale can help assess pain.

The Abbey Pain Scale, Dr. Burgess noted, is specially designed to help assess pain in people who cannot verbally articulate their feelings. This tool enables the user to assess the patient based on observations related to vocalizations, facial expressions, changes in body language, behavioral changes, physiological changes, and physical changes. It is designed to be used as a movement-based assessment. So the patient should be observed when he or she is being moved, during pressure area care, while showering, while eating, and during other care activities. Then a second evaluation should be conducted one hour after any intervention is undertaken.

Other scales that can be used with cognitively impaired patients include the Pain Assessment in Advanced Dementia (PAINAD) and the Pain Assessment

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If We Don’t Diagnose…
The consequences of missing or ignoring signs of pain in cognitively impaired patients are significant, Dr. Burgess said, and they include:

- Poor appetite and/or weight loss
- Disturbed sleep
- Fatigue
- Withdrawal from talking or social activities
- Detachment from relationships with family or friends
- Anger
- Sadness, anxiety, or depression
- Physical and verbal aggression
- Resisting care
- Wandering
- Loss of self-esteem
- Skin breakdown, ulcers
- Incontinence
- Increased risk for use of chemical and physical restraints

Untreated pain also may cause patients to have decreased ability to perform activities of daily living, less ability to function, and more difficulty walking or transferring. They also may experience impaired immune function, hormonal imbalance, and increased fall risk. As a result of any combination of these, they may become bedbound.

There are also consequences for the facility, staff, and practitioners. Dr. Burgess noted. These include survey tags, citations, and penalties, negligence/malpractice lawsuits, readmissions, negative press, and loss of referrals and reputation.

Team Tags In
“Pain management requires an ongoing team approach, and it must include measurable goals for pain control,” said Dr. Burgess. It’s an “all-hands-on-deck situation,” he suggested, that requires ongoing assessments by everyone. At the same time, he said, “We need to make sure that we set realistic expectations for pain and that we get everyone on the same page. The goal is to reduce pain to a functional level.”

Any approach to pain management must include nonpharmacologic as well as pharmacologic interventions, and it must consider the patient’s preferences and effectiveness. While each player on the care team has a specific role, Dr. Burgess suggested that everyone can show they care, listen, and empathize. They also can talk to the patient, even if he or she doesn’t understand, and — as possible — educate the patient and family about pain goals and treatment. They can set realistic comfort-function goals for the pain.

All team members can be “cheerleaders” for patients, encouraging them to pursue physical therapy or other interventions and helping them understand the importance of reporting pain. Not only should the team members communicate with the patient and family, they also should communicate with each other, Dr. Burgess said.

Marijuana in Nursing Homes
AMDA – The Society for Post-Acute and Long-Term Care Medicine has recently updated its position on the use of marijuana in nursing homes. The Society supports patient-centered decision making, including the use of marijuana when it has substantial clinical benefits that justify the risks, but it cautions against the widespread use of marijuana in the long-term care setting. The updated position statement is available online at http://bit.ly/32GPH4P.

Pain management, particularly in patients with cognitive impairment, is a journey, with many stops and many different players. Bring your team together, Dr. Burgess suggested, and uncover all the information you need to effectively manage pain in people who often can’t speak for themselves.

Creating a Person-Centered Culture: The Key to Finding Home

Each one of us starts our culture exchange journey by learning, growing, and experiencing “a-ha moments” in a way that touches us personally. On my personal culture change journey, I have been fortunate enough to visit quite a few communities across the country where I experienced those moments. Have you ever walked into a community and had that a-ha feeling — that here is a community where they have truly created home?

Dementia Care Matters
For me, the most recent a-ha experience was last spring when I had the opportunity to play hooky for a few hours while attending the annual conference of AMDA — The Society for Post-Acute and Long-Term Care Medicine in Atlanta. I paid a visit to Park Springs, a Life Plan Community in Stone Mountain, GA. I spent a few wonderful hours experiencing their community, including their Garden and Lake Households, whose residents are living with dementia in the only Dementia Care Matters Butterfly Home in the United States.

I had heard of the great work being done by Andy Isaksen, the owner and operator of the community, and that prompted me to make this visit because I wanted to see just what this “Butterfly Model” was all about. Reading about this model had been inspiring, but as we all know theories are great, but the proof is in the seeing — and in this case, the feeling!

What was it about Park Springs that created this feeling of home? It was the smiles, and it was hearing each member (that’s what they call both staff and residents) as they greeted Andy, who hosted my visit, with smiles and hugs. It was listening as he called them each by name and shared stories and reminisced with them.

The colors on the walls were bright, and the decor looked like it had been designed by the people who lived there, with meaning in the furnishings and the decorations on the walls. Park Springs had a pace that was easy, not rushed, and was centered around taking the time to be with the residents. The staff seemed to be confident in who they were and how they interacted with all the members, Something like pet therapy that can bring tremendous joy to one person may be boring or even upsetting to someone else.

Medication Management
Of course, pharmacologic interventions don’t have to mean opioids. Nonsteroidal anti-inflammatory drugs (NSAIDs), acetaminophen, topicals, steroids, and cannabinoids all may be used with varying levels of efficacy. Other treatments may include muscle relaxants, anticonvulsants, antidepressants, and nonopioids. Again, these must be customized to each person’s pain, comorbid conditions, and other issues. This comes back to the value of the initial assessment and the need to assess patients continually over time.

Pain management, particularly in patients with cognitive impairment, is a journey, with many stops and many different players. Bring your team together, Dr. Burgess suggested, and uncover all the information you need to effectively manage pain in people who often can’t speak for themselves.

Senior contributing writer Joanne Kaldy is a freelance writer in Harrisburg, PA, and a communications consultant for the Society and other organizations.

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Checklist for Seniors with Limited Ability to Communicate Revised (PACSLAC-II)

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