More than six months after the SARS-CoV-2 virus began its spread through the United States, nursing home leaders and staff feel battered. If not their own facilities, their peers and their industry have been blamed, fined, and investigated for the outbreaks of COVID-19 that have occurred while they did not have adequate access to personal protective equipment (PPE) or tests and in the face of conflicting — and some say, convoluted — guidance from public health officials regarding testing and sites for post-acute care.

Having borne the brunt of the virus’s impact in their high-density populations of mostly old, frail individuals, who often have dementia and other multiple comorbidities, nursing homes have become “a scapegoat for our chronic disregard of our elders and [underfunding of long-term care],” said James Wright, MD, PhD, CMD, medical director of the Canterbury Rehabilitation and Healthcare Center in Richmond, VA. “What I see isn’t anger about how society treats elders. It’s anger that’s directed toward facilities.”

How to change this — how to grow a better understanding of long-term care, how to move away from a persistently punitive regulatory approach, and ultimately how to shift public perception and create a shared sense of responsibility and support for long-term care — is on the minds of nursing home leaders and advocates as they make their way through the pandemic.

The future of long-term care depends on our ability to explain to the society and stakeholders what LTC is and what it needs to be successful.

Most immediately, experts in geriatrics and long-term care must be “fully engaged” with government and the industry in deciding how to best protect elders, said Mike Wasserman, See NURSING HOMES • page 11

As the devastation of the COVID-19 pandemic continues to unfold and the death rate begins to take shape with accurate reporting and more frequent testing, David Grabowski, Ph.D., a researcher at Harvard Medical School’s Health Care Policy Department who studies nursing homes, says that when the final data are in, nursing homes will probably account for about half of all COVID-19 deaths in every state — as they already do in Massachusetts, New Jersey, and Pennsylvania, among others (New York Times, May 5, 2020, https://nyti.ms/3cwZGC5). This global health crisis has increased the need to swiftly identify a resident’s preferences for medical treatment.

Health care providers who specialize in palliative care (PC), a medical specialty focused on advance care planning and symptom management in serious illness, have been eager to bring their skill set and resources to the frontlines, especially to the post-acute and long-term

See PANDEMIC • page 14

A Burden of Being A Hero
Being regarded as a hero may contribute to unrealistic expectations that may be detrimental to the health care worker. 3

Your Facility’s Best Advocate
Could nursing home leaders have been insufficiently proactive in demanding resources and support during the COVID-19 pandemic? 4

Beneficence vs. Autonomy
Discharges against medical advice are challenging, but they can be successful. 9

Information Lifeline
A grassroots medical director association becomes an invaluable information source for New York practitioners. 13

Good Death
As the fear of dying alone has become a reality for many nursing home residents, “good” death is still possible during the pandemic. 18

Palliative Care Amid the Pandemic: Resources for PALTC Providers and Families
By Melissa McClean, MSN, ANP-BC, ACHPN, and Victoria Nalls, GNP-BC, CWS, ACHPN

Join the only medical specialty society representing practitioners working in the various post-acute and long-term care settings.

Visit paltc.org/membership to learn more!
Pandemic
from page 1

care setting. Interventions such as initiating discussions to address goals of care and using therapies to relieve distressing symptoms (physical, social, and/or spiritual) are concepts inherent in PC, and they are vital to the care of older adults with COVID-19.

Although the delivery of PC differs throughout PALTC, there are multiple ways PC concepts can support health care professionals engaged in the care of seriously ill or dying residents. We review the resources and modalities used by PC providers in the response to COVID-19 to help in educating patients, families, health care colleagues, and the general public about what PC is and how these specialized clinicians contribute to the care of PALTC residents.

Online resources
Multiple evidence-based resources to prepare and educate both patients and health care professionals have been created, and they are freely available during this pandemic. Table 1 provides a list of commonly used medical and PC resources for health care professionals. VitalTalk and the Serious Illness Conversation Guide provide evidence-based, tailored questions to ask during serious illness conversations. VitalTalk also offers practical videos that demonstrate how to discuss these questions. VitalTalk and the Center to Advance Palliative Care (CAPC) both also have serious illness conversation guides and symptom management resources specifically targeted to COVID-19. Palliative Care Fast Facts also offers quick references for symptom management. The use of these resources may be helpful if a PALTC facility does not have a dedicated PC provider and wishes to offer additional support to the residents’ families or to further educate PALTC staff.

Table 1. Resources for Patients and Families

<table>
<thead>
<tr>
<th>Name</th>
<th>Website</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conversation Project</td>
<td><a href="https://theconversationproject.org/">https://theconversationproject.org/</a></td>
<td>Start-up kits for serious illness conversations; COVID-19-specific kits available</td>
</tr>
<tr>
<td>Five Wishes</td>
<td><a href="https://fivewishes.org/">https://fivewishes.org/</a></td>
<td>Information for both patients and providers; easy-to-use legal advance directive; COVID-19-specific information available</td>
</tr>
<tr>
<td>My Living Voice</td>
<td><a href="https://www.mylivingvoice.com/">https://www.mylivingvoice.com/</a></td>
<td>Step-by-step resource to create an online advance directive (can be printed)</td>
</tr>
<tr>
<td>POLST</td>
<td><a href="https://polst.org/">https://polst.org/</a></td>
<td>Patient-focused website of POLST forms and resources</td>
</tr>
</tbody>
</table>

Table 2. Palliative Care Resources for Health Care Providers

<table>
<thead>
<tr>
<th>Name</th>
<th>Website</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>VitalTalk</td>
<td><a href="https://www.vitaltalk.org/">https://www.vitaltalk.org/</a></td>
<td>Website or smartphone app that provides specific examples of questions to use during serious illness conversations; COVID-19-specific questions available</td>
</tr>
<tr>
<td>CAPC</td>
<td><a href="https://www.capc.org/toolkits/covid-19-response-resources">https://www.capc.org/toolkits/covid-19-response-resources</a></td>
<td>Free COVID-19 resources (other trainings require membership)</td>
</tr>
<tr>
<td>POLST</td>
<td><a href="https://polst.org/professionals-page/">https://polst.org/professionals-page/</a></td>
<td>Health care professional website for POLST forms and resources</td>
</tr>
<tr>
<td>Conversation Guide</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative Care Fast Facts</td>
<td><a href="https://www.mypcnnow.org/fast-facts/">https://www.mypcnnow.org/fast-facts/</a></td>
<td>Website or smartphone app with quick facts for symptom management (Note that some areas have not been updated since 2015.)</td>
</tr>
<tr>
<td>Social Work Hospice &amp; Palliative Care Network (SWHPN)</td>
<td><a href="https://www.swhpn.org/covid-19">https://www.swhpn.org/covid-19</a></td>
<td>Resources for social workers to aid with serious illness conversations</td>
</tr>
<tr>
<td>AMDA Telehealth Resources</td>
<td><a href="https://paltc.org/node/6297">https://paltc.org/node/6297</a></td>
<td>List of links to telehealth resources</td>
</tr>
</tbody>
</table>

Telehealth consultations
Because not all PALTC facilities can support an in-house PC team due to lack of resources and funding (Palliat Med 2020;34:555–557), PC consult teams can bridge the gap for PALTC patients, families, and staff. After PALTC facilities were urged to protect their vulnerable residents by limiting the entry of external personnel, PC teams made rapid, drastic changes to their practice to remain in contact with patients and families.

Like many other health care professionals, PC providers have incorporated the use of video technology. Video conferencing over platforms such as Zoom and FaceTime have facilitated interactions to provide comfort or closure in otherwise impossible situations. PC providers have successfully connected patients with their families, regardless of their location, through telehealth and mediated serious conversations. They’ve also supported patients and families through final goodbyes.

In addition, software that supports electronic signatures is being used to

For more information or to order your copy, please visit paltc.org.

GUIDE TO POST-ACUTE AND LONG-TERM CODING, REIMBURSEMENT, AND DOCUMENTATION

The Society’s Guide to Post-Acute and Long-Term Care Coding, Reimbursement, and Documentation contains documentation requirements and Society-developed coding vignettes for each of the nursing home family of codes as well as Chronic Care Management (CCM), Advance Care Planning (ACP), and Behavioral Health Integrated (BHI) services.
Lack of Evidence Complicates Care for Nursing Home Residents With Epilepsy

By Christine Kilgore

There’s mixed news for the diagnosis and management of epilepsy in nursing homes, where the prevalence of the disorder is estimated to be more than seven times higher than among seniors in the community.

Generally speaking, for instance, the main evidence-based guideline on management of an unprovoked first seizure in adults — published by the American Academy of Neurology and American Epilepsy Society (Neurology 2015;84:1705–1713) — is applicable to the nursing home population. That’s good news, as is the development of a broader and “practical” definition of epilepsy by the International League Against Epilepsy (ILAE), two epilepsy specialists said at the Annual Conference of AMDA – The Society for Post-Acute and Long-Term Care Medicine.

What is vexing — and what represents a “huge hole” for clinicians caring for nursing home residents with epilepsy — is the lack of evidence to guide the appropriate use of antiseizure medications in this population, the speakers said.

“I don’t necessarily have evidence that any of [newer] drugs are actually really better than others,” said Ilo Leppik, MD, during a question-and-answer session that focused largely on drug choice and questions about therapeutic monitoring. “Levetiracetam and lamotrigine appear to be better for the elderly, especially in nursing homes, but we just don’t have the data.”

The 2015 guideline on management of an unprovoked first seizure does not discuss drug choice but rather decision-making about whether to initiate therapy immediately. Level A evidence supports that recurrence risk is greatest early within the first two years (21% to 45%), the guideline states. Clinical variables associated with increased risk include a previous brain insult, including stroke (level A); an electroencephalogram with epileptiform abnormalities (level A); a significant brain-imaging abnormality (level B); and a nocturnal seizure (level B).

“Immediate antiseizure therapy compared with a delay pending a second seizure is likely to reduce the recurrence risk for the first two years but may not improve the quality of life due to medication side effects,” said Dr. Leppik, professor of neurology and pharmacy at the University of Minnesota, in reviewing the guideline. He said that, interestingly enough, immediate treatment is unlikely to improve the long-term (>3 years) prognosis for seizure remission.

The guideline is not as applicable to the nursing home population when it comes to adverse event risks. The guideline reports a risk of drug-related adverse events of 7% to 31% and advises that the effects are predominantly mild; however, Dr. Leppik said, “in the nursing home the side effects may be more than mild because of preexisting issues with cognition.”

Levetiracetam is probably the “most widely used antiseizure medication for the elderly, including in my practice,” Dr. Leppik said during the question-and-answer session. The drug has “definite advantages ... but it causes the most issues with behavior. For that reason alone, I’m not convinced it’s the best drug to use in the nursing home setting.”

Rebecca O’Dwyer, MD, assistant professor in the Department of Neurological Sciences at Rush Medical College in Chicago, agreed that levetiracetam’s side effect profile is concerning — particularly, based on her experience, in patients with frontal lobe epilepsy. “It’s helpful to know where the seizures are coming from,” she said, noting that she also often uses lamotrigine. “It’s anecdotal, but I sometimes feel that people with temporal lobe epilepsy are less susceptible to those negative side effects [of levetiracetam].”

When asked about newer agents such as eslicarbazepine acetate (Aptiom) and lacosamide (Vimpat), Dr. Leppik cautioned that “industry is really pushing Aptiom for the elderly, but it’s in the family of carbamazepine and occarbazine, and all three of these drugs have a propensity for lowering sodium levels.”

Therapeutic drug monitoring in the elderly requires a high level of individualization, Drs. Leppik and O’Dwyer emphasized. Asked about the importance of titrating antiseizure agents based on blood levels versus on seizure control, Dr. Leppik cautioned that “therapeutic range is a lab range value and can be very misleading” in the elderly population.

“It needs to be individualized,” he said. “We know from experience that the elderly generally need lower blood levels because, for one, their seizures seem to better controlled [with lower levels], and secondly they seem to get side effects at lower levels than other adults.”

Dr. Leppik said he was securing funding for a national survey of medical directors to learn more about how new-onset epilepsy is managed in the nursing home.

His prior research has helped define the epidemiology of epilepsy in the nursing home population. In 2017, Dr. Leppik and his coauthors reported in an analysis of all residents in all Medicare/Medicaid–certified nursing homes that the point prevalence of epilepsy/seizures was 7.7%, and that prevalence is 7 to 30 times higher in individuals with certain comorbid neurologic conditions. (Neurology 2017;88:750–757).

Christine Kilgore is a freelance writer based in Falls Church, VA.

Continued from previous page

complete crucial documents such as do not resuscitate (DNR) orders, POLST, and hospice election forms. These examples of innovative care delivery would not have been possible without flexibility and cooperation on the part of PC providers and PALTC staff to give patients appropriate, working access to this technology.

The impact of COVID-19 has been devastating in PALTC, and serious illness conversations and advance care planning have never been more critical. How the COVID-19 pandemic will impact the long-term delivery of health care remains unclear, but one thing is certain: incorporating PC concepts into the care of individuals with chronic, life-limiting illnesses across all health care settings empowers both patients and families, allowing them to have more information and perhaps a plan for when the unimaginable occurs.

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