ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, AND SERVICES

Washington, DC

April 29, 2019

WELCOME AND CHARGE FOR MEETING

Laura Gitlin, Ph.D., Chair
Dr. Gitlin opened the meeting at 9:05 a.m. She thanked everyone for coming and invited members to introduce themselves. Ellen Blackwell, Susan Cooley, Bruce Finke, Joan Weiss, and Allan Levey joined by telephone.

COUNCIL BUSINESS: MEASURING PROGRESS, RECOMMENDATIONS, AND MOONSHOT UPDATES

Laura Gitlin, Ph.D. and Helen Lamont, Ph.D., Designated Federal Officer

- Nominations for replacements of Advisory Council members whose term expires will be posted in late May or early June. She encouraged members to think about good additions for the Council, reminding them that they need new chairs for the Advisory Council and for the Clinical Care and Research Subcommittees. She would like these people to overlap with current chairs so they can have the benefit of a mentoring process. The July meeting will be a transition time.
- *Robert Egge, Alzheimer's Association*, will send a draft executive summary to accompany the 2018 recommendations.
- The Council will receive a report on the March ADRD Summit at the next meeting.

Mr. Egge announced that the House committee will mark up their appropriation bills on Tuesday. The House and Senate subcommittees have the same ask: $250 million for research at the National Institutes of Health. Legislation introduced includes the following:

- HIV Organ Policy Equity Act.
- Supporting American Caregivers and Families Act.
- CHANGE Act, which focuses on detection and diagnosis.
- Younger onset and nonnarcotic medications in nursing homes.

Mr. Egge is looking for opportunities to have a briefing about dementia issues with new Congressional members. *Dr. Gitlin* thought active legislation may inform the work of the National Alzheimer's Project Act (NAPA) Advisory Council subcommittees and asked for a list of them. *Mr. Egge* will send it to her to disseminate to the Advisory Council.

Debra Cherry, Ph.D., reported that Medicare Advance plans will have higher capitation rates for people with a dementia diagnosis, which offers a real opportunity to encourage early diagnosis and advanced care plans.

Dr. Gitlin reminded the subcommittees that they should continue to meet and develop recommendations for July, using the 2018 recommendations as a starting point.

Dr. Lamont encouraged subcommittee members to review their measures of progress to ensure the proposed measurements align with evaluation strategies.

Dr. Gitlin reported that the Moonshot Group met last week. This group intends to build on existing evidence that can make a real difference in the lives of people with dementia and their caregivers. They talked about prevention, but discussion gravitated to improving life for persons living with dementia (PLWD). Eight ideas emerged from the brainstorming session. Now the group will scrutinize the eight ideas and at the next session they will pick the most promising and will devise strategies. At the next meeting, the Council will begin discussion of what happens after 2025.

Dr. Epstein-Lubow suggested recommending that the Council's work be continued. He wants to clarify that language and will bring results of the subcommittee's discussions to the Council in July. *Cynthia Huling Hummel* offered to draft the recommendation. *Dr. Gitlin* wants the recommendation to continue this discussion to be in the public record.

Courtney Wallin reported that plans for the Dementia Care and Services Summit are progressing. She reported that David Reuben, M.D., University of California-Los Angeles, and Jennifer Wolfe, Ph.D., Johns Hopkins University, will co-chair the Dementia Care and Services Summit.

IMPLEMENTING PERSON-CENTERED PLANNING TO SUPPORT PEOPLE LIVING WITH COGNITIVE SYMPTOMS

Session 1: Person-Centered Planning for People with Complex Conditions

Gary Epstein-Lubow, Chair of Clinical Care Subcommittee
Dr. Epstein-Lubow provided as context for today's sessions the National Plan's mandate to carry out annual assessments in preparing for increased incidence of Alzheimer's disease (AD) as the United States population ages.

The National Center on Advancing Person-Centered Practices and Systems (NCAPPS) and the National Quality Forum's (NQF's) Person-Centered Planning and Practice

Shawn Terrell, Administration for Community Living (ACL)

Within HHS, some 15 policy documents already require person-centered planning (PCP). ACL has a vision for person-centered practices and systems that embraces:

- People know what to expect.
- Competent planning facilitation.
- Systems deliver services and supports in a manner consistent with person-centered values.
- Quality measures developed and implemented for process fidelity, experience, and outcomes based on each person's preferences and goals.
- Principles of continuous learning applied throughout the system.
- Formalized and ongoing partnerships with people with disabilities and older adults in designing and implementing person-centered thinking, planning, and practices in systems.

ACL is addressing these challenges through NCAPPS, NQF's PCP Project, and the Person-Centered Advisory and Leadership Group (PAL-Group). NCAPPS webinars, given by experts, are free and open to the public. In addition, ACL offers technical assistance and learning collaboratives to promote peer-to-peer learning.

The NQF PCP Project consists of a 25-person, multi-stakeholder committee (culled from 300 applicants). They are refining the current definition for PCP, developing a set of core competencies, making recommendations to HHS, developing a conceptual framework for PCP measurement, and conducting an environmental scan to define a research agenda. Eight webinars will be given May 3, 2019, through June 2020. Meanwhile the PAL-Group enables ACL to receive input from people with lived experience.

Driving Change: The Why and How of Advancing Person-Centered Outcome Measurement

Gretchen Alkema, Ph.D., The SCAN Foundation

Health systems respond to the measures they are required to collect. For example, to comply health care providers may need to take an A1C measurement to test for diabetes. But what does getting that sample mean for the person with cognitive impairment? Consumers' vision of success is more likely centered on being able to lead the best life they can with the least amount of intervention; having their needs met in a timely, organized, and convenient manner by competent providers; and having confidence in navigating the care system by themselves or with support when needed.

People with cognitive impairment may also be dealing with many other conditions. Moreover, functional impairment is associated with high medical spending, particularly for those with three or more chronic conditions. The health care universe thinks the medical interventions are most important, whereas patients think function--measured by the difficulty of performing activities of daily living--is most important. The business case for person-centered care is that it will increase quality while it decreases cost.

Person-centered care is defined with the individual at the center. A person's preferences and values guide all aspects of health care and support realistic health and life goals (e.g., dementia is unlikely to disappear). Then care can be coordinated as appropriate. Meanwhile, education and training are given to providers and recipients around the person-centered care experience.

The old caregiving paradigm was driven by the provider; the new paradigm is driven by the user. "What's the matter with you?" becomes "What matters to you?" The single provider focus and approach become a customer service approach, and provider action becomes consumer confidence and functional outcomes.

Ultimately, what matters is functional outcomes, not the disease state. What matters to the patient may be whether she or he can attend a granddaughter's graduation, not various cardiac measurements.

Accountability for Person-Centered Care Planning: Performance Measurement and Accreditation

Jessica Briefer French, National Committee for Quality Assurance (NCQA)

Creating and sustaining meaningful changes requires more than good intentions. Payment systems, quality measures, and training all need to align for person-centered care planning. Health care quality measures may produce outcomes that are not meaningful to the individual. Individuals want health care to support their life goals rather than add to the burden of living. To do that, care planning must focus on what matters most to the patient. Therefore, NCQA convened focus groups to determine goals that are important to the individual with the following result:

- Stay out of the hospital.
- Manage physical symptoms (e.g., control pain).
- Have legal and financial affairs in order.
- Return to the home setting.
- Practice religion and spirituality.
- Have more free time for the caregiver.
- Not be a burden on the family.
- Maintain or regain independence.

The process starts with a conversation with the patient to determine time-bound goals (also known as smart goals). Goal attainment scaling allows the person to target a desired outcome (e.g., getting to church, walking to the end of the block) and that goal becomes the basis for care planning. At a determined interval, patient and provider meet again to assess progress, and either continue or adjust the goal or the way to achieve it.

Healthcare Effectiveness Data and Information Set (HEDIS)® 2019 is a set of measurements widely adopted by managed care facilities. Four new components have been added for long-term services and supports (LTSS): comprehensive assessment and update, comprehensive care plan and update, shared care plan with primary care practitioner, and reassessment/care plan update after inpatient discharge. NCQA has offered three LTSS accreditation programs since July 2016, launched a fourth in January 2017, and has defined accreditation standards for eight measurements. LTSS 3 is Person-Centered Care Planning. These standards have facilitated engaging people with less experience. People with serious illness are working with the project team and all the work is vetted through the individual for whom the care is intended.

Comments and Questions

Mr. Egge asked whether a conversation was taking place about payment scaling for reimbursement of the main outcome. *Ms. French* said it is not about goals; the emphasis is on what a person wants to do. Implicit in all care is that individuals want to be healthy so they can do what is important to them. When they have multiple chronic conditions, it is hard to know which condition is the driving force. Issues are in sight, but it is too early to know how to maneuver through the obstacles.

When the hospital caregivers told *Dr. Gitlin's* 90-year-old mother she had been discharged, she refused to go because no one had asked for her personal goals, which she had not achieved. Research on eliciting goals and targeting treatment has much relevance to this area and there is much information in the research literature.

Question: Is there discussion about a certificate indicating that the facility has been designated a person-centered care facility? *Dr. Alkema* acknowledged that some of the work around person-centered care involves education and public relations. Although people generally like the concept of person-centered care, most patients are not aware of what it entails. We need a person-friendly hallmark to characterize such long-term care facilities. *Mr. Terrell* agreed that work on this is needed. We need to know what kind of systems' characteristics should be in place to support person-centered care. *Ms. French* said NCQA's LTSS programs do that. One of the eight core components is person-centered care services. Another concern is how to manage the proliferation of expectations, such as recognizing programs for people being treated in their homes. NCQA is working on extending systems that are already in place for cancer to other conditions that require long-term care.

Becky Kurtz: How does technical assistance get to those with lived experience? Can federal funds be used for this? *Mr. Terrell* replied that states create policies that determine how that can be done. The systems-change piece is being modified at every level and those results will get to persons with lived experience.

Bradley Hyman, M.D., said that some of the most difficult situations involve end-of-life care. How can discussions about this be put into the complex medical environment? *Ms. French* thought that the person-centered approach with people with serious illness does just that. Their discussions cover the expected trajectory and the patient's experience, goals, and outcomes. However, it takes time to transition from delivering bad news to discussing goals. Patients have goals even at the end of life (e.g., they may want to attend an event or lessen the burden on their caregivers). NCQA is now trying this with a small set of organizations to see how it works.

Recommendations

Dr. Epstein-Lubow thanked the organizers and participants and noted that the work today directly ties to Recommendation 10 from 2017: devote one meeting to the work the HHS Office of the Assistant Secretary for Planning and Evaluation has conducted with RTI International on defining best practices for comprehensive dementia care.

In 2018, NAPA put forward Recommendations 4 and 5:

- Recommendation 4. Determine a process for reaching consensus on national definitions of best practices for comprehensive care of Alzheimer's disease and related dementias (AD/ADRD) at all disease stages.
- Recommendation 5. Encourage further development, evaluation, and use of health care models for AD/ADRD that align performance measures, the experience of care by persons living with AD/ADRD and their caregivers, and payment.

Elements are consistent across several models, so the issue is how these elements can be consistently provided to caregivers and PLWD, and how agencies and providers can collaborate. New national resources and quality measures will be helpful.

Session 2: Practical Implementation of Person-Centered Planning for People Living with Cognitive Symptoms

Person-Centered Planning in Dementia Care

Soo Borson, M.D., University of Washington School of Medicine [via telephone]
There has been training in psychiatry centers on efficacy and relational care, which frequently comes into play with dementia care. Clinical practice is about uncertainty management. However, getting doctors to do something differently is tough.

There are five domains of person-centered dementia care: cognition, mental and emotional health, physical health, key friends and family, and social determinants. Centers for Medicare & Medicaid Services (CMS) developed a cognitive assessment code, CPT 99483, to be performed by physicians and non-physician practitioners to evaluate a patient with cognitive impairment. CMS convened the Alzheimer's Association Workgroup, an interprofessional collaboration, to explain in plain language the purpose and elements of CPT 99483, encourage uptake in primary care by illustrating simple ways to meet the nine elements, identify gaps, and anticipate potential barriers to use.

Key innovations of the code include that it acknowledges complexity; explicitly includes caregivers; requires a written, shared care plan; offers good value for providers and health systems; and allows combination with other codes. (Dementia care requires a tremendous amount of non-reimbursable caregiver time.)

Caregivers need to know something about co-conditions and they need to know about the situations faced by the individual's friends and families. These areas are typically reserved for non-medical providers, but they must be included to ensure continuity of care. Person-centered tool development should also address payment incentives. So far, the person's and family's experience of care is not reflected in any key element.

Dementia Care Planning in Medicare: Use of the Care Planning Code

Matthew Baumgart, Alzheimer's Association

Medicare reimburses providers for dementia care under Code G0505. Analyzing these Medicare data reveals use trends. With 18,669 fee-for-service (FFS) and 2,857 Medicare Advantage users, the utilization rate was 55.6/100,000 individuals, but fewer among Medicare Advantage plans. In context, the estimated prevalence of AD among those 65 or older in 2017 was 5.3 million. In 2017, FFS with diagnosed AD/ADRD for all ages numbered 3.7 million. In 2011, the estimated incidence of AD among people 65 and older was 910,051.

If dementia is not diagnosed, there is no care plan. Likewise, if it is diagnosed in late stages there may be no care plan. In 2017, fewer than 1% received care planning. Women were more likely than men to receive a care plan. For both FFS and Medicare Advantage most users of the code were between 75 and 84 years old, but the 65-74 age group was outperforming in use of the code. Younger people are likely to be in earlier stages of the disease.

Providers who bill for Code G0505 numbered 1,208 FFS vs. 539 Medicare Advantage. For both (but in different order), the top five providers specialized in internal medicine, neurology, family practice, nurse practitioner, and geriatric medicine. The FFS top two providers (internal medicine and neurology) accounted for 51% and for Medicare Advantage the top two providers (family practice and internal medicine) accounted for 65%. When a claim is filed for Medicare, the primary diagnosis for which the patient is being treated is used for categorization. A general medical exam was the primary reason for a visit to the doctor for Medicare Advantage, which implies that practitioners see dementia as part of the general examination they give.

People generally seem to recognize the connection between high blood pressure and cognitive impairment. Usage trends increased by month at nearly the same rate for both types of insurance. Possible questions for future work include:

- How many who receive care planning are newly diagnosed? And how many under 65 are newly diagnosed?
- What subsequent services do those with care planning receive?

- After a care plan has been established, is there a billing code for the Medicare Advantage planning benefit?
- Recipients were unanimous in restrictions on care planning. Is utilization of services continuing?
- Do those who receive care plans have fewer hospitalizations and emergency room visits?

Sowande Tichawonna asked why the District of Columbia (DC) has no users of G0505. *Mr. Baumgart* replied that DC has a younger population, and it may also have to do with Medicare administration and how things are being pushed.

Care Planning and Health Information Technology--Exemplars

Arlene Bierman, M.D., M.S., Agency for Healthcare Research and Quality (AHRQ)
AHRQ envisions a sustainable health care system that delivers high-value coordinated care and support. The system should be integrated patient-centered care based on primary care and should optimize individual and population health by preventing and effectively managing multiple chronic conditions. It strives to be a bridge between people with patient-centered care and their various health care providers. Patients manage multiple conditions, all of which impact care and care planning. Therefore, care plans must be developed for patients with multiple conditions.

AHRQ and the National Institute of Diabetes and Digestive and Kidney Diseases, along with multiple federal partners, have embarked on a project to determine how this can be done. This project will build capacity for pragmatic, patient-centered outcomes research by developing an interoperable electronic (e)Care Plan to facilitate aggregation and sharing of patient-centered data across home, community, clinic, and research settings. The project is designed to improve interoperability of data for research and care, and to address the challenge of critical but missing patient information. With such a plan, data can be developed once and used for multiple purposes.

Dementia Care 3.0

Malaz Boustani, M.D., Indiana University Medical School
An effective dementia care plan requires a plan and distribution channel. The care strategy for Dementia Care 3.0 is evidence based. The plan addresses caregiver stress prevention, medication management, and transition care. It includes a messaging tool that connects caregivers with the health care system. Within the messaging tool, the project created a training video. After nearly 2 years of ethnographic observations, a prototype was developed, and by filling in the evaluation forms, caregivers can help develop this. The Mobile Health component makes caregivers more readily available.

Leveraging a Person-Centered Collaboration Platform: Connecting People and Plans to Ensure Progress

Alexandra Greenhill, CaseTeam Technologies

CaseTeam Technologies has developed a technological approach to using care planning. A coordination care team treats all the various conditions. While 99% of health care happens at home and in the community, most research money is spent on studying clinics.

People with dementia should have annual hearing and vision tests, but only 8% get them because they simply are not able to do so. They come to a clinic because they fell or sustained some other injury. Collaboration cannot occur unless they have a director (co-directors are better) and a plan. Patient-reported outcome offers a huge opportunity.

In Canada, electronic devices are being purchased through the Ottawa Champlain Network, which includes 22 community organizations. They use the Dementia+ Model, but each community uses its own plan and customizes the software. With this technology, all the information is available on any device, but for the devices to be effective, they must have human-centered design. This can help anyone involved in coordination.

Innovations in the Delivery of Dementia Care in a Rapidly Evolving Health Care Landscape

Brent Forester, M.D., M.Sc., McLean Hospital, Partners HealthCare, Harvard Medical School

Partners HealthCare collaborates with commercial insurers, as well as federal health care agencies. The challenges of dementia diagnosis start with primary care. It is estimated that only about half of the people with AD have been diagnosed. The intent is to focus on the patient to provide better, not more, care. To provide better dementia care, primary caregivers need education in diagnosis and management.

A needs assessment identified four challenges: distinguishing dementia from depression and normal memory loss, discussing dementia and delivering the diagnosis, managing behavioral symptoms and medications, and accessing specialty care when indicated. Opportunities include improved care coordination, connection of patients to resources in the community and at Partners HealthCare, advance care planning, and caregiver support and access to resources.

The aims of the Partners Memory Care Initiative are to support and train primary care providers, improve patient health outcomes and caregiver health status, and reduce health care costs. To do this they have established a care team that collaborates with the primary care provider. Partners eCare is an interdisciplinary patient plan of care. Information is shared within, but not outside the collaborative.

Comments and Questions

Question: How can an initiative have concurrent goals about getting primary care clinicians to deal with dementia? *Dr. Boustani*: It cannot be done because these caregivers are not empowered and they are burned out. Until policy creates the market demand, it will not happen. We need to create a concrete demand, similar, for example, to the demand for bone marrow transplants, in which society created the demand for the several-hundred-thousand-dollar transplants. *Ms. Greenhill*: Adoption is the key. Physicians adopt the tools they need, but they need preexisting experience to do that. We can help them be successful with training and by monitoring the impact of their work on the patient. Scale-up should not be done too fast and certainly not until the innovation is known to work. We also need to stop the mindset that a single solution works for everything. *Dr. Bierman*: We need to invest in research and collaboration to fund this process.

Angela Taylor: Where do you integrate what the caregiver needs? How do they benefit from person-centered care? *Dr. Boustani*: Caregiver needs and client needs do not compete. We monitor caregiver stress, much of which is outside the caregiving sphere.

Debra Cherry, Ph.D., asked whether there were problems with compliance with the Health Insurance Portability and Accountability Act (HIPAA). *Dr. Boustani* said a consultant can evaluate all the liability risks, not just HIPAA, but that implies secure communication. And this sort of technology is getting cheaper. *Ms. Greenhill* agreed that now electronic security is cheap enough for most people. HIPAA clearly states that patients have a right to their own records.

PUBLIC INPUT

Diana Blackwelder, PLWD

- At age 55, Ms. Blackwelder was diagnosed with younger onset AD and because of her age she is excluded from many caregiving and support options.
- Even as PLWD forget some of their life and professional experiences, those experiences have shaped who they are, and that does not fade away. Feelings, emotions, and intelligence remain intact, and care planning needs to leverage and respect these things.
- PLWD need to be empowered to maximize and extend their self-sufficiency for as long as possible, even if it increases risk to themselves.
- Ms. Blackwelder strongly advocates that care plans consider leveraging nontraditional support systems.
- The Smithsonian's "See Me" and the National Gallery of Art's "Just Us Programs" have both been restarted and expanded.
- The DC government's services receive at least partial funding through grants from the Older Americans Act and it is this funding source that sets an age restriction on services that excludes people with younger onset AD.

Susan Peschin, Alliance for Aging Research

- Shared decision-making is critical to person-centered care and should become the standard for informed consent in health care.
- There is a high unmet medical need in dementia care for diagnosis and treatment of neuropsychiatric symptoms such as agitation.
- Depression is one of the earliest observable symptoms in AD and may worsen as dementia increases. Agitation is another early symptom, but data-driven information is lacking, as it is for the benefits and drawbacks associated with bifurcating treatment for psychosis and agitation.
- The Food and Drug Administration issued a warning for use of atypical antipsychotics in the treatment of neuropsychiatric symptoms in older patients with dementia. However, it has been shown that the primary correlate of negative outcomes is the psychiatric symptomatology and not the drugs used to treat them.
- The Alliance for Aging Research would like the opportunity to convene this summer with CMS and relevant stakeholders to help initiate practical recommendations prior to implementation of the last phase of the mega-rule prohibiting use of antipsychotics.

Jadene Ransdell, National Task Group on Intellectual Disabilities and Dementia Practices

- Facilities care for patients with primary AD/ADRD, or Parkinson's and dementia, etc., but legally they cannot keep a patient with idiopathic dementia in Down syndrome and secondarily Down dementia in a facility with more than eight beds.
- Studies show that people with Down syndrome face accelerated aging and thus, in their 40s and 50s, have health care needs more closely resembling those of people in their 60s and 70s, including increased risk of AD.
- Ms. Ransdell strongly urged the Council to continue to push for full inclusion of people with Down syndrome and AD in all federally-funded community programs and research.

Matthew Sharp, Association for Frontotemporal Degeneration

- It is convenient to think that different types of dementia conform to the names we have given them. In fact, most dementias are pathologically mixed. Now the role of TDP-43 in various forms of dementia has been revealed in an entirely new disease entity called limbic-predominant age-related TDP-43 encephalopathy (LATE).
- Mr. Sharp urged the Council to dedicate one of the non-governmental organization seats to a representative from an Alzheimer-focused organization and the other to a group that focuses on the related dementias.

MaryAnne Sterling, Sterling Health IT Consulting

- Person-centeredness includes the ability of families to access affordable home health care seamlessly, but that has not been her experience.
- When Ms. Sterling's mother turned to social services to get additional support for her husband, she was told that the U.S. Department of Veterans Affairs (VA) and

Medicaid do not work together. Furthermore, if she accepted caregiving support that is paid for by Medicaid, she would have to give up the caregiver provided by the VA.

- It took relentless advocacy of both a local social worker and a case manager to get the VA to increase the number of hours of home care from 6 to 16 per month.
- Ms. Sterling calls upon the Council to simplify access to home care services.

Clair James, Georgia State University [read by Dr. Lamont]

- Current technology can improve the quality of lives of PLWD. As persons with dementia begin to lose their autonomy and ability to reason, assistive technology and human enhancement can be key to maintaining their personhood and decision-making potential.

Thaddeus Flood, Otsuka America Pharmaceutical [read by Dr. Lamont]

- Behavioral health issues may stem from varied sources and should be addressed differently based on the underlying cause. Federal policies should support thorough evaluation and treatment of patients with behavioral health issues living in long-term care facilities.
- For behavioral health issues related to underlying serious mental illness, such as depression, bipolar disorder, or schizophrenia, antipsychotic medications are on-label for these uses and federal policies should not restrict appropriate access to these medications for patients for whom they are in fact appropriate.
- For behavioral health associated with AD, such as agitation, non-pharmacologic interventions should be considered first to address other potential underlying causes and factors. Exceptions should be made in the case of emergent or acute episodes, or for patients currently stabilized on an antipsychotic for a previously diagnosed or co-occurring mental illness.
- Antipsychotic medications should be used with dementia-related behaviors unresponsive to nonpharmacologic interventions.
- Nonpharmacologic approaches should be evaluated for the potential to permit treatment with lower doses of antipsychotic medications.
- Federal policies should recognize and support appropriate and necessary use of antipsychotic medications for patients with neuropsychiatric symptoms.
- For antipsychotic use in long-term care facilities, policies should evaluate on-label and off-label use differently.
- Policy frameworks can and should differentiate between the use of antipsychotics for sedation or chemical restraint, both serious forms of patient abuse, and for the treatment of mental illness and dementia-related neuropsychiatric symptoms that improve patients' quality of life.
- Clinical indications and effectiveness should be reviewed periodically for all medications, including antipsychotics. Gradual dose reduction may be contraindicated for some patients whose behavioral symptoms are currently stabilized or who have a serious mental illness.
- Behavioral symptoms clinically diagnosed as "agitation" include restlessness, significant emotional distress, aggressive behaviors, and irritability. Symptoms of agitation in AD are associated with significant burden and negative health, social,

and economic consequences for patients and their caregivers. Agitation is often a determining factor in the decision to place patients in high-level residential care facilities, contributing to the roughly $259 billion cost burden of AD in the United States.
- Behavioral symptoms present a dilemma to clinicians and care providers in a long-term care setting since disruptive or dangerous behavior requires attention and resources that are not always available, whereas treatment of symptoms of agitation reduces caregiver burden and the cost of care for the patient.

SESSION 3: ADDRESSING DETAILS OF TREATMENT, INCLUDING ANTIPSYCHOTIC MEDICATION USE AND CASE EXAMPLES

Inappropriate Use of Antipsychotics for People with Dementia in Community Settings

Anita Everett, M.D., and Matthew Goldman, M.D., M.S., Substance Abuse and Mental Health Services Administration (SAMHSA)

Behavioral manifestations of dementia--agitation and aggression--are common and require careful assessment and management. Physical and psychiatric causes of behavioral symptoms should be identified and treated accordingly. Goals of care should be discussed when dementia results in behaviors that endanger the individual or their caregivers. A clear person-centered care plan should be made with specific behavior modification strategies. Nonpharmacologic approaches to care should always be attempted first unless clinically contraindicated. These include helping PLWD maintain a routine schedule, avoiding demanding tasks, engaging in activities that are important to the person, and focusing on creating a positive environment.

If antipsychotics are required to counter dangerous behaviors, risks and benefits should be discussed with the PLWD and family to obtain informed consent; second generation antipsychotics are preferred; dosage should be started as low as possible with modest increases only when clinically indicated; symptoms and side effects should be monitored closely; medications should be discontinued through tapering, when necessary; and tapering with close monitoring should be attempted for all patients within 4 months of treatment.

Most efforts related to the National Partnership to Improve Dementia Care in Nursing Homes have focused on antipsychotic use in nursing homes. However, many PLWD are in community settings and their medications are often prescribed by primary care providers. Co-morbidities include underlying causes as well as psychiatric afflictions. It is not appropriate to replace an antipsychotic with an alternate class of medication. Preventing caregiver burnout is an important issue, but the effect on caregiver burnout of treating PLWD with antipsychotics is not known.

The *National Plan to Address Alzheimer's Disease* specifically call out:

- Action 2.D.1: Explore dementia care guidelines and measures. Consider expanded use of quality metrics focused on antipsychotic prescribing in dementia (e.g., NQF 2111).
- Action 3.D.1: Monitor, report, and reduce inappropriate use of antipsychotics in nursing homes. Consider expanding action to include people living outside nursing home settings.

Shari Ling, M.D., Centers for Medicare & Medicaid Services (CMS)

"Guidance on Inappropriate Use of Antipsychotics" was produced by SAMHSA, CMS, ACL, and the Health Resources and Services Administration. This is a national action plan. There are numerous opportunities for us to help the system do the right thing. First, we need to know the impediments. Then, knowing the goals, we can develop a care plan around those goals. We may not know how or what to do, but we have to do it. Framing goes beyond the nursing home, but the principles are applicable over the entire field.

Weighing of risks and benefits illustrates the importance of being able to measure, and measurement relies on data. In the nursing home space, we have only put forth quality measurements and data concerning antipsychotic use. Principles beyond the nursing home are not so easily applicable to the community. Data from Data Medicare and the National Cancer Institute (2013-2016) can be used to understand the impact of frequency of antipsychotic prescriptions.

CMS must include a requirement for person-centered care in care plans. It is part of the expectation to be included in Medicare reimbursement.

Comments and Questions

Mr. Tichawonna: It always boils down to communication and training. Because these are low-paying jobs, the bar is so low. Most staff have English as a second language, which complicates communication. *Dr. Ling*: Communication should be bi-directional. What can the recipient of care ask of people providing that care? For example, signs that say, "If you haven't seen your health care provider wash her hands, ask if she did." That empowers the patient. They may lack awareness.

Dr. Gitlin: The patient-provider interaction occurs in a complex environment. It is about knowledge and education of our health care providers. In the system of care, there is some evidence available that, for example, a quick huddle helps. Some methods go back years, so we have a serious scaling problem. But, a problem is not caused by just one thing. Generally, we are talking about organization and education. A nonpharmacological treatment in the home often depends upon a care partner for implementation. In person-centered care, the assessment of the care partner is imperative--Is she or he employed? What is their ability and availability?

Ms. Taylor: This underscores the importance of being able to scale up. You cannot scale up one tool without scaling up the others. We should have early intervention for the caregiver as well as for PLWD. With antipsychotics there is an added sensitivity risk, but there is a place for them. Parkinson's disease and psychosis are what gets people sent to care facilities. *Dr. Epstein-Lubow*: That is true for both for adults and younger people.

Dr. Goldman: Although the science for the two populations differs, many of the resulting problems overlap. There is a need for increased awareness when going from one treatment to another. Impediments include the fact that these are not easy conversations to have. Providers need training for that. It is scary for all involved to embark on a de-prescribing program. Health care providers need retraining, and everyone needs communication from outcome to discharge. *Dr. Everett*: These discussions should include comments on the recent medical schedule. Some description of the purpose might be useful as part of the discharge planning document, along with guidance for the home stay.

Ms. Kurtz: What is the difference between the nursing home care, in-home care, and long-term care settings? In a nursing home we know there is overuse of drugs, but patients have a long-term care ombudsman, a director of nursing, a pharmacologist, etc. None of that exists at home, but there might be a care partner. The care partner has such a heightened role that this person must be given training. People deliver meals, etc., to the home, but the medical community has no contact with those people at all. The political side and the social services side have no way to connect. *Dr. Ling* agreed. Solutions are not "either/or," but "and."

Person-Centered Dementia Care Planning and Antipsychotic Use: Panel Discussion

Moderators: Cynthia Huling Hummel and Katie Brandt

Ms. Hummel introduced the session and invited panelists to share their experiences and then discuss the importance of having a person-centered care plan, which should include a medication schedule, including antipsychotics if necessary.

Greg O'Brien, writer, was diagnosed several years ago and because he does not fit the ADRD pattern he has found it difficult to get treatment. He has made clear in his medical plan that he wants to be in charge and wants to stay at home as long as possible. He wrote *On Pluto: Inside the Mind of Alzheimer's*.

Mr. O'Brien takes several medications, but he will not take more despite the fact that he feels alone, sometimes suicidal, and does not sleep well. Medications' side effects slow down his thinking. He considers medications pockets of reserve. Now neuroplasticity has been discovered so we can hope to train the brain.

E. Jennifer Brown, Family Caregivers and Coordinator of Advocacy, New Jersey Council on Developmental Disabilities. The central tenet of patient-centered care philosophy is to include the person in all discussions and decisions. We want to help people live in their own community within their own cultural competency, to keep people connected to their life.

Ms. Brown thinks antipsychotics should be used as a last resort. She and her husband held off as long as possible before accepting antipsychotics for their son. Within the care plan there is a clear directive to every person involved in their son's care including nontraditional modalities, such as art lessons. Caregivers must be supported and technology allows caregivers to easily share information via the telephone with all the other caregivers. But they must also understand the function and purpose of the medication.

Shawn Terrell, ACL. Mr. Terrell's mother and father had dementia of two different kinds. When his mother moved to a care facility, he wrote a 20-page care plan; no one read it. Years later when his father needed similar care, Mr. Terrell distilled the care plan to a one-page profile that included, in addition to medication information, what people like about him, the kind of person who could best work with him, etc. This approach helped people support him.

When Mr. Terrell visited his mother in her assisted living facility, he noted that she had a glazed look and discovered she had been given Haldol, but no one seemed to know why. He and his sister demanded that she be titrated off. They had learned a lot by the time his father was in similar need, which made everything easier.

Ms. Brandt suggested the simple action of introducing the patient to the caregiver, thereby recognizing their personhood.

FEDERAL WORKGROUP UPDATES

Administration for Community Living (ACL)

Erin Long

- ACL awarded nine expansion grants for 18-month programs (e.g., occupational health, enhanced partnerships, caregiver support, behavioral symptom management for linguistically diverse and lower literacy caregivers, and dementia training and education for physicians and health care workers).
- For the RAISE Act, invitations to nominated and selected Council members were mailed in late March. Acceptances are in ethics review and are being vetted as Special Government Employees. ACL is engaged in the procurement process to secure a logistics contract to assist with convening the Council and supporting their work. There is also work underway to fund establishment of a resource and dissemination center to support the work of Council.
- The National Alzheimer's and Dementia Resource Center is hosting a series of ten webinars. Ms. Hummel will present next week.

- The National Center for Law and Elder Rights (NCLER) has resources on diminished capacity and AD. NCLER offered two webinars: Advance Planning Documents and Using Consumer Law to Protect Nursing Facility Residents.

Indian Health Service (IHS)

Bruce Finke, M.D. [by telephone]

- The Greater Los Angeles Area is reestablishing training and mentoring for caregiver coaches (REACH into Indian Country).
- The VA Office of Rural Health continues to provide Rural Interdisciplinary Team Training for IHS and Tribal sites.
- The Centers for Disease Control and Prevention (CDC) produced an infographic on American Indian/Alaska Native (AI/AN) caregiving and AI/AN subjective cognitive decline.
- CDC and the Alzheimer's Association will release the Healthy Brain Initiative Road Map for Indian Country at the National Indian Health Board meeting May 13-14.
- On April 2, the conference Honoring Elder Wisdom, which was held in Walker, Minnesota, focused on ADRD.
- Next week there will be a presentation at the Secretary's Tribal Advisory Committee meeting on the status of AD care and information in Indian Country.

Center for Disease Control and Prevention (CDC)

Lisa McGuire, Ph.D.

- CDC and IHS have produced Data for Action--aggregate infographics for 49 states, DC, and Puerto Rico. So far, topics are Subjective Cognitive Decline and Caregiving. These have also been adapted to AI/ANs, African Americans, and Latinos.
- The Healthy Brain Initiative Road Map has been issued for state and local public health.
- CDC has produced a series of communication materials in collaboration with the Association for State and Territorial Health Officials (ASTHO) and Tribal organizations (e.g., the importance of managing blood pressure). These are available on ASTHO's website and will also be on CDC's website. In addition, a series of public service announcements have been developed for radio.

Centers for Medicare & Medicaid Services (CMS)

Shari Ling, M.D.

- The CMS Administrator, Seema Verma, has issued a blog on nursing home quality.
- The National Partnership to Improve Dementia Care in nursing homes has resulted in an overall 38% decrease in antipsychotic use, but only 5% for "late adopters."

- Nursing Home Compare helps people choose a facility. That information can be used with Census data to indicate staffing ratios, etc.
- Medicaid home and community-based services revised its criteria and outlined factors that determine whether a setting isolates beneficiaries.

Agency for Healthcare Research and Quality (AHRQ)

Arlene Bierman, M.D.

- Evidence syntheses are in progress and have been posted on the web. So far, they are: Diagnosis and Treatment of Clinical Alzheimer's Type Dementia, and Care Interventions for People with Dementia and Their Caregivers.
- New evidence syntheses, expected to be issued in 2020 are: Prevention, Diagnosis, and Management of Inappropriate Opioid Use, Misuse, and Abuse in Older Adults; and Integrating Palliative Care with Chronic Disease Management in Ambulatory Care.
- AHRQ is working on a 5-year agenda to address multiple chronic conditions. This will involve research, data-driven tools, and nationwide dissemination and implementation. In the process, they are listening to stakeholders to fine tune the agenda.

National Institute on Aging (NIA)

Richard Hodes, M.D.

- NIA will have some 140 clinical trials in the pipeline by 2025; amyloids account for 35, but so far results have been disappointing.
- Genetic regions of interest have been identified in AD.
- Accelerating Medicines Partnership for Alzheimer's Disease has, among other things, established a centralized data resource portal, developed a network model of disease pathways and targets, and identified more than 100 novel candidate targets.
- Alzheimer's Disease Centers for Discovery of New Medicines received applications in February. NIA plans to commit some $75 million over 5 years to support two centers.
- An AHRQ-National Academies of Science study assessed interventions to prevent AD, mild cognitive impairment (MCI), and age-related cognitive decline. It found insufficient evidence to justify a public health campaign, but found encouraging evidence to encourage cognitive training, blood pressure management in hypertensives, and physical activity.
- The SPRINT randomized clinical trial was conducted to address the question of whether intensive blood pressure control reduces the occurrence of dementia and found a 19% reduction in the rate of developing MCI and a 15% reduction in the rate of composite MCI and probable dementia.
- Planning for the March 2020 Care/Caregiving Research Summit is underway. *Mr. Jordan* announced that there will be seven sessions and subjects are being developed with lots of public input.

- NIA is offering the iCare-AD/ADRD Challenge to Improve Care for People with AD/ADRD Using Technology. Submissions of software technologies will be accepted October 1, 2018, to June 30, 2019. The prize will be as much as $400,000.

CONCLUDING REMARKS

Dr. Gitlin raised the only question for federal partners: What is CMS doing about the decrease in use of antipsychotics? *Dr. Ling* said CMS processes for each entity must change with the nature of the disease.

Dr. Gitlin adjourned the meeting at 4:28 p.m.

The next NAPA meeting will take place on July 2019.

Minutes submitted by Helen Lamont (ASPE).
All presentation handouts are available at http://aspe.hhs.gov/advisory-council-alzheimers-research-care-and-services-meetings.

PARTICIPANTS

Advisory Council Members

Present
Arlene Bierman, M.D., Centers for Medicare & Medicaid Services
Ellen Blackwell, Centers for Medicare & Medicaid Services *[via telephone]*
Katherine Brandt, Massachusetts General Hospital
Debra Cherry, Ph.D., Alzheimer's Greater Los Angeles
Susan Cooley, Ph.D., Department of Veterans Affairs *[via telephone]*
Robert Egge, Alzheimer's Association
Bruce Finke, M.D., Indian Health Service *[via telephone]*
Gary Epstein-Lubow, M.D., Brown University
Laura Gitlin, Ph.D., Drexel University, Chair
Richard Hodes, M.D., National Institute on Aging/National Institutes of Health
Cynthia Huling Hummel, Person Living with Dementia, Elmira, NY
Bradley Hyman, M.D., Alzheimer's Disease Research Center
Becky Kurtz, Atlanta Regional Commission, Area Agency on Aging
Helen Lamont, Ph.D., Designated Federal Officer, Office of the Assistant Secretary for Planning and Evaluation
Allan Levey, M.D., Emory University *[via telephone]*
Shari Ling, M.D., Centers for Medicare & Medicaid Services
Erin Long, Administration for Community Living/Administration on Aging
Lisa McGuire, Ph.D., Centers for Disease Control and Prevention
Deborah Olster, Ph.D., National Science Foundation
Arne Owens, Office of the Assistant Secretary for Planning and Evaluation
Anthony Pacifico, Ph.D., Department of Defense
Marianne Shaughnessy, U.S. Department of Veterans Affairs
Angela Taylor, Lewy Body Dementia Association
Sowande Tichawonna, Caregiver, Washington, DC
Joan Weiss, Ph.D., Health Resources and Services Administration *[via telephone]*

Absent
Michelle Dionne-Vahalik, Texas Health and Human Services Commission
Billy Dunn, U.S. Food and Drug Administration
Anthony Pacifico, Ph.D., Department of Defense
Marianne Shaughnessy, U.S. Department of Veterans Affairs

Public

Speakers

Gretchen Alkema, Ph.D., SCAN Foundation *[via telephone]*
Matthew Baumgart, Alzheimer's Association
Soo Borson, University of Washington *[via telephone]*
Malaz Boustani, Indiana University
E. Jennifer Brown, Family Caregivers and Coordinator of Advocacy, New Jersey Council on Developmental Disabilities
Anita Everett, M.D., Substance Abuse and Mental Health Services Administration
Brent Forester, M.D., Harvard Medical School
Jessica Briefer French, National Committee for Quality Assurance
Matthew Goldman, Substance Abuse and Mental Health Services Administration
Alexandra Greenhill, CaseTeam Technologies
Gregg O'Brien, Writer, Person Living with Dementia
Shawn Terrell, Administration for Community Living

Attendees

Diana Blackwelder
Erin Cadwalader
Phil Cronin
Sam Fazio
Molly French
Jordan Gladman
Kate Gordon
J. Taylor Harden
Anisha Imhoff-Kerr
Matthew Janicki
Melinda Kelley
Ian Kremer
William Martin
Cindy McConnell
Heather Menne
Douglas Pace
Susan Peschin
Duncan Pettigrew
Jadene Ransdell
Matthew Sharp
Eric Sokol
Mary Anne Sterling
Sarah Smith Tellock
Salom Teshale
Laura Thornhill
Courtney Wallin
Marion Weisse