Improving Care for Patients with Alzheimer's Disease

Dec 16th, 2024
1:30pm-3:00pm ET | 10:30am-12:00pm PT
Meeting Summary

On December 16th, 2024, the Duke-Margolis Institute for Health Policy, in collaboration with West Health, hosted a private roundtable on the topic of Improving Care for Patients with Alzheimer's Disease. A diverse group of stakeholders—including payers, patient advocates, manufacturers, dementia specialists and sub-specialists, and researchers—came together to discuss potential short- and long-term opportunities to transform Alzheimer's disease (AD) care and payment by identifying current barriers and priorities.

Dr. Mark McClellan opened the meeting with a background overview of the current clinical and policy landscape. Dr. McClellan described the current fragmented and reactive care delivery for AD, in which patients and caregivers are often responsible for care navigation. Both medical and non-medical interventions are available to help patients maintain quality of life and independence, but do not change the course of the disease. Early-stage monoclonal antibody (mAb) treatments have recently been introduced to the market with the potential to slow disease progression, but there are outstanding questions regarding long-term outcomes and impacts on certain populations that require additional evidence development to inform appropriate use, and per CMS policy, to provide full Medicare coverage. Dr. McClellan also highlighted the opportunities of the new CMS Innovation Center (CMMI) model, Guiding an Improved Dementia Experience (GUIDE), which features support for care navigation and respite care for caregivers. This model uses a per-member per-month care management payment that is based on disease severity and other factors (such as caregiver resources) on top of the fee-for-service structure. While the GUIDE model is a step in the right direction for AD care, there may be additional steps that can help support comprehensive, longitudinal, whole-person AD care.

During the first session, participants discussed some of these potential short- and long-term steps to improve AD care. Stakeholders generally agreed that one of the key barriers to receiving appropriate, timely care for AD is diagnosis, which frequently occurs later than when certain interventions would be helpful for individuals living with AD. Additionally, the GUIDE model tends to focus on more complex or high-need populations, meaning these individuals tend to be in mid-to late-disease stages. Participants therefore generally agreed that supporting earlier diagnosis and early-stage disease management is a critical opportunity. Participants noted that current care delivery, including delivery of novel therapeutics, can be poorly reimbursed and administratively complex, which adds burden to an already stretched workforce. In the short-term, stakeholders may want to consider how technology may help improve efficiency, especially for administrative tasks. As a long-term step, stakeholders showed enthusiasm for creating an AD registry that goes beyond outcomes for individuals on mAb treatments. The registry would encompass a broader focus, tracking long-term outcomes, such as quality of life throughout disease progression. Such a registry might also help more accurately estimate total cost of care throughout the stages of the disease.

The second group discussion explored potential research directions that may be most impactful, given the current clinical and policy landscape. Dr. Marianne Hamilton Lopez posed some potential directions for research around an AD care model, including focusing on a particular disease stage, integrating with the GUIDE model or proposing a standalone model, and focusing the scope of services to supporting therapeutic use or offering a wider set of services. Participants highlighted that there may be opportunities to learn from existing value-based care models, such as the Coordinated Care Model, and apply effective elements to an AD care model. Participants agreed, especially given current CMMI reforms, that a model focused on early-stage disease holds significant potential to be the most impactful. However, participants raised concerns that any potential cost-savings from early interventions may not be seen for many years later. This may make investments in early-stage interventions, including therapeutics, riskier for payers. Research may need to focus on how early interventions improve patient outcomes and quality of care, may be cost-effective or cost-neutral, at what point payers may begin to see cost savings, and whether these interventions are underutilized.

Duke-Margolis looks forward to continued engagement to build on these discussions on improving access to comprehensive care and novel therapeutics.