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Toward Gerineuropalliative Care for Patients with Dementia

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Today, an estimated 6.7 million people over 65 years of age in the United States are living with dementia, cared for in part by 11 million unpaid care givers.[1] Globally, more than 55 million people have dementia, and 10 million new cases are diagnosed each year.[2] New anti-amyloid and emerging anti-tau therapies are focusing attention on early screening and diagnosis for dementia syndromes, which are progressive serious illnesses. In parallel with new treatments, however, we need new care models that can mitigate suffering, enhance care quality, and expand support for persons living with dementia and their care partners — goals that are aligned with the U.S. National Plan to Address Alzheimer's Disease[3] and the World Health Organization's Global Action Plan on the Public Health Response to Dementia.[2]

To achieve these goals, we propose a "gerineuropalliative" approach to dementia that would infuse principles from geriatric, palliative, and dementia care into every stage and aspect of care, regardless of the discipline of the clinician involved (see figure). Just as advances in cancer treatments (e.g., immunotherapy) have increased the salience of geriatrics and palliative care for treating the whole person, the advent of disease-modifying treatments for dementia makes gerineuropalliative dementia care more pressing, given potentially burdensome treatment protocols and side effects, prognostic uncertainty, and the need to navigate discoordinated health care.

As things stand, Americans with dementia and their care partners face extensive care gaps and fragmentation, even if they are well-resourced and can access clinics associated with Alzheimer's disease research centers.[4] Specialty memory care clinics provide diagnosis and annual appointments focused on medical management; even when they are available, psychosocial supports are insufficient to address all patients' needs. In interviews, persons with dementia and their care partners described their need for adaptive support in managing progressive changes in distressing behavioral symptoms, function, and social connections.[4]

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Interviewees said they wanted prognostic information and anticipatory guidance specific to dementia to inform their treatment decisions, financial planning, home adaptations, and transitions between settings.

Clinical dementia specialists, for their part, report that attending to the palliative care needs of people with dementia is aligned with their core practices, but barriers include lack of training and discomfort in having difficult conversations. Many persons with dementia live at home, often for years, with substantial functional and medical needs. Qualitative and quantitative data reveal that functional and social changes associated with disease progression contribute to loss to follow-up from office-based care. Hospice care for persons with dementia is available at home and improves last-month-of-life experience,[5] yet hospice programs often adhere to a shorter-term cancer-based model. There are few alternatives providing long-term, interdisciplinary, home-based care supporting adaptation to incremental functional decline and evolving needs of both patient and care partner.

Gerineuropalliative dementia care, as we envision it, would draw on various disciplines to address the full needs of persons with dementia and their care communities. It would combine the existing field of neuropalliative care with attention to geriatric syndromes and applies the combined gerineuropalliativecare principles to dementia. Comprehensive geriatric care has similar goals, but the approach we propose would capitalize on a confluence of knowledge and skills that extend beyond traditional geriatric care. Gerineuropalliative dementia carewould combine core principles from all relevant disciplines: geriatrics-informed care, including attention to multiple coexisting conditions, function, and care transitions; palliative care communication skills to support prognostic and anticipatory guidance; and neurology-informed diagnostic skills that incorporate use of biomarkers, neuroimaging, and neuropathology. Emerging research suggests that different types of dementia result in different trajectories of decline, behavioral manifestations, and responsiveness to pharmacologic treatment. Persons with less common types of dementia and their care partners appreciate type-specific prognostic and management information.

The figure outlines evidence-based recommendations for care domains relevant to each stage of dementia, along with structures for implementing gerineuropalliative dementia care. The timing of activities will differ from this schema for certain subpopulations — and may change as new disease-modifying treatments emerge. For example, new therapeutics may lead to targeted screening and earlier diagnosis. Rapidly progressive dementias require more compressed evaluation and management strategies. And people with dementia who are dying from another serious illness have different supportive care needs than people dying from dementia alone.

Given the fractured nature of the U.S. health care system, inequities in access, and inconsistencies in entry points, we would envision all clinicians using this integrated approach. Growing disease prevalence will outstrip specialty care capacity and necessitates a generalist model of gerineuropalliative dementia care. In an environment where there are limited numbers of specialists and a growing number of older adults with dementia, the concepts incorporated into each specialty will need to be broadened.

Moreover, primary care providers cannot address all needs of patients with dementia in the currently allotted visit time. The ideal approach would be to ensure that every member of the interprofessional team was competent in core principles of gerineuropalliative dementia care and integrated them into their specific scope of practice. Such an approach could be implemented by health care systems charged with the overall care of patients, such as managed care plans. Population health programs could identify at-risk populations and ensure appropriate screening, evaluation, and longitudinal care of persons with dementia and their care partners. Within academic centers, primary care clinicians could work with specialists to develop efficient workflows for collaborative care. Dementia care programs could address all domains of gerineuropalliative care, provide toolkits and best-practice recommendations, and serve as resources for all clinicians.

Establishing a robust, competent workforce would require initial and ongoing training in gerineuropalliative dementia care, using both asynchronous and synchronous interactive methods. All relevant disciplines and professions have something to teach — and something to learn — about optimal dementia care. Medical and nursing specialty fellowships in geriatric care, palliative care, and behavioral neurology could incorporate training in competencies specific to gerineuropalliative dementia care. The Aliviado Health program (from the Hartford Institute for Geriatric Nursing at New York University's Rory Meyers College of Nursing) trains long-term care and hospice team members in dementia care principles. The Care Ecosystem (developed with a grant from the Center for Medicare and Medicaid Innovation [CMMI]) trains care team navigators in dementia care, embeds navigators within a clinical team and provides the team with dementia-specific care protocols.

Caring for older adults with dementia and their care partners is complicated, time-consuming, unpredictable, and also rewarding. Ambulatory clinics reimbursed on a fee-for-service basis are not a good match for needed care. In order to enable high-quality, goal-aligned care, we believe new payment models are required to provide reimbursement for all members of interdisciplinary teams (including chaplains, home health aides, physical and occupational therapists, psychologists, social workers, and others) in all care settings.

In July 2023, CMMI announced a new 8-year test of an alternative payment model for supportive care for persons living with dementia and their unpaid caregivers, called Guiding an Improved Dementia Experience (GUIDE). It facilitates care for patient–partner dyads by providing a standardized set of services in home and community-based settings, delivered by an interdisciplinary team with dementia competence and coordinated by trained care navigators. It also helps caregivers access respite care and 24/7 caregiver support. Payment tiers are adjusted for the complexity of dyad needs (or lack of caregiver), and a one-time lump sum is available for program infrastructure development. Programs can use our proposal for gerineuropalliative dementia care when implementing the GUIDE Model. Over time, the GUIDE Model or similar payment models will ideally provide incentives for acquiring and maintaining competence in gerineuropalliative dementia care and assuring care quality. In addition, dyads will need community-based long-term services such as home health aides, home-based primary care, "hospital at home," and hospice care.

The effort required to accomplish this ambitious paradigm shift would be substantial. Yet we need to consider the cost to society of failing to achieve the goal of mitigating suffering for this population, given that the United States may be home to more than 13 million people with dementia by 2060.[1] We now have an opportunity to build the dementia care system that we would want for our loved ones and ourselves.

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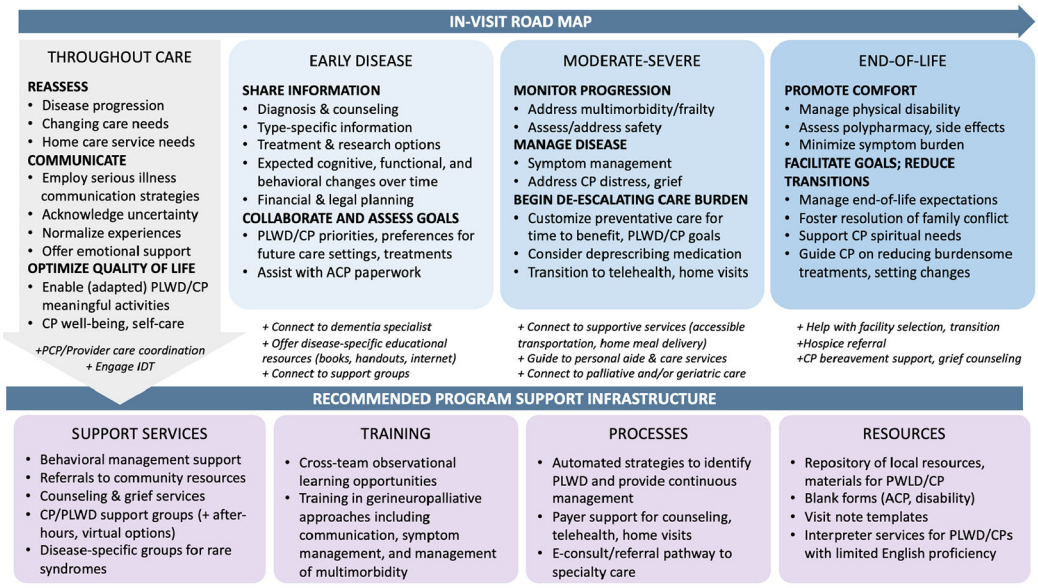

Figure. Gerineuropalliative Dementia Care across the Disease Continuum.

Recommendations for gerineuropalliative dementia care, based on synthesized qualitative and quantitative research. Most persons living with dementia will need items listed in the "early disease" box addressed before those in the "moderate-to-severe" box, but tasks such as assessing goals and priorities will continue to be relevant at all stages. ACP denotes advance care planning, ADL activities of daily living, CP care partner, IDT interdisciplinary care team, PCP primary care provider, and PLWD person living with dementia.