American Academy of Hospice and Palliative Medicine
Outside Witness Testimony Prepared for the Senate Committee on Appropriations
Subcommittee on Labor, Health and Human Services, Education, and Related Agencies
Fiscal Year 2025 Appropriations for the National Institutes of Health/National Institute on Aging

Chair Baldwin, Ranking Member Capito, and members of the Subcommittee, the American Academy of Hospice and Palliative Medicine (AAHPM or Academy) appreciates the opportunity to provide outside witness testimony and stands ready to work with the Committee to advance sound policy that improves care and quality of life for millions of Americans facing serious illness, along with their families and caregivers. We greatly appreciate your leadership investing in palliative care research and thank you for including $12.5 million in the *Further Consolidated Appropriations, 2024* for the National Institute on Aging (NIA) to implement a trans-Institute, multi-disease strategy to focus, expand, and intensify a national research program in palliative care. **In fiscal year (FY) 2025, AAHPM requests $12.5 million for the NIA to coordinate the work of the trans-Institute, multi-disease Consortium for Palliative Care Research Across the Lifespan.** Ongoing bipartisan, bicameral, and steadfast leadership has been instrumental in realizing this step to strengthen the commitment to support patients facing serious illness and their families.

AAHPM is the professional organization for physicians specializing in Hospice and Palliative Medicine. Our more than 5,200 members also include nurses, social workers, spiritual care providers, and other health professionals deeply committed to improving quality of life for the expanding and diverse population of patients facing serious illness, as well as their families and caregivers. Together, we strive to advance the field and ensure that patients across all communities and geographies have timely access to high-quality, equitable palliative and hospice care. For more than 30 years, AAHPM has been dedicated to advancing the discipline of Hospice and Palliative Medicine through professional education and training, development of a specialist workforce, support for clinical practice standards, research, and public policy.

BACKGROUND

The U.S. Census Bureau projects that the population aged 65 and over will approximate 83.7 million by 2050, almost double that in 2012. As the population ages, the number of people living with serious, complex, and chronic illness will continue to grow. (Serious illness is a health condition that carries a high risk of mortality and either negatively impacts a person's daily functioning or quality of life or excessively strains their caregivers.[1]) Many of the problems of our healthcare system – high costs, overutilization, lack of coordination, preventable transitions between healthcare institutions, and poor quality – become particularly evident during extended chronic and serious illness. We believe palliative care offers the solution.

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Palliative care is an interdisciplinary model of care aimed at preventing and treating the debilitating effects of serious and chronic illness – such as cancer, cardiac disease, respiratory disease, kidney failure, Alzheimer's, ALS, and MS – and involves the relief of pain and other symptoms that cause discomfort, such as shortness of breath and unrelenting nausea. Palliative care is patient- and family-centered – it focuses on matching treatment to achievable patient goals and supporting patients and their families/caregivers during and after treatment to maximize quality of life. In practice, this involves detailed and skilled communication with patients and families to elicit goals and preferences; expert assessment and management of physical, psychological, and other sources of suffering; and coordination of care across the multiple settings (e.g., hospital, post-acute care, ambulatory clinics, home) that patients can often traverse throughout the course of a serious illness. Palliative care can be provided from the time of diagnosis and offered alongside life-prolonging and curative therapies for individuals living with serious, complex, and eventually terminal illness. Hospice care is palliative care tailored for individuals near the end of life.

AAHPM believes that palliative care providers and organizations, including hospices, are integral to meeting the "triple aim" of better care for individuals, improved health of populations, and lower growth in health care expenditures. Indeed, the National Priorities Partnership has highlighted palliative and end-of-life care as one of six national health priorities that have the potential to create lasting change across the U.S. healthcare system.

An expanding body of medical research has documented the benefits of high-quality palliative and hospice care for patients and families, for hospitals and payers, and for the healthcare system as a whole.[2] Palliative care is associated with enhanced quality of life for patients, higher rates of patient and family satisfaction with medical care, reduced hospital expenditures and lengths of stay, and other positive outcomes – including longer patient survival time. Furthermore, palliative care achieves these outcomes at a lower cost than usual care, by helping patients to better understand and address their needs, choose the most effective interventions, and avoid unnecessary/unwanted hospitalizations and interventions. Hospice care has also been associated with lower cost of care, better outcomes (such as relief of pain), and even longer life, despite its focus on comfort rather than treatment aimed at cure.

Still, too many patients with serious illness experience tremendous physical and psychosocial suffering and, unlike areas of medicine focused on curing or preventing disease, the evidence base for relieving suffering and improving quality of life for seriously ill patients and their caregivers is inadequate.[3,4] To ensure that the millions of Americans with serious illness and their families/ caregivers receive the high-quality care that they need and deserve, more research is needed to better understand and address pain and other distressing symptoms related to serious illness, and to improve serious illness care delivery models, communication science, and caregiving science. We also know there are significant disparities in palliative and end-of-life care. New research holds the potential to reduce these disparities in the care of people living with serious illness and their families by integrating historically excluded patients and examining the role of social determinants of health — which for palliative care include loneliness, food access, poverty and financial toxicity, and insufficient or unsafe housing — in care delivery, quality, and outcomes.[5]

FY 2025 APPROPRIATIONS FUNDING AND REPORT LANGUAGE REQUESTS

Research related to palliative care and serious illness crosses nearly every Institute, Center, and Office (ICO) at the National Institutes of Health (NIH), but also poses challenges because it does not fit neatly within a single ICO. The Academy appreciates that Congress included report language urging the NIH to develop a trans-Institute strategy for increasing funded research in palliative care for persons living with chronic and advanced illness in the Labor, Health and Human Services, Education, and Related Agencies (LHHS) appropriations reports in FY 2011, FY 2019, and the *Consolidated Appropriations Act, 2023*. We are optimistic that the funding and recent language for FY 2024 will help improve coordination and expand activities related to palliative care research across NIH.

For FY 2025, AAHPM requests that the Subcommittee include $12.5 million in the LHHS Subcommittee funding bill for the NIA and the trans-Institute, multi-disease Consortium for Palliative Care Research Across the Lifespan. Additionally, to build on ongoing efforts of the NIH and NIA to establish the Consortium for Palliative Care Research Across the Lifespan, we offer the language below for consideration as part of the report to accompany the FY 2025 LHHS appropriations:

> ***Palliative Care Research*.—The Committee provides $12,500,000 for NIA to coordinate the work of the Consortium for Palliative Care Research Across the Lifespan, including developing early and mid-stage researchers, and engaging various healthcare systems, providers, and community partners. The Committee recognizes that palliative care is a critical area of research and informs supportive care for patients of all ages with serious illness and their families focused on relief of symptoms and suffering, communication of prognosis and treatment options in the context of patient goals, and coordination of care within and across healthcare settings.**

The Academy thanks the Subcommittee for previous report language and requests funding in FY 2025 to support NIH's continued efforts to realize the goal of enhancing palliative care research to improve care and quality of life for the expanding and diverse population of patients with serious illness, as well as their families and caregivers.

REFERENCES

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[3] National Academies of Science Engineering and Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. The National Academies Press; 2015:1-612.

[4] Brown E, Morrison RS, Gelfman LP. An Update: NIH Research Funding for Palliative Medicine,2011-2015. *J Palliat Med*. Feb 2018;21(2):182-187.doi:10.1089/jpm.2017.0287

[5]"Palliative Care In The Face Of Racism: A Call To Transform Clinical Practice, Research, Policy, And Leadership", Health Affairs Forefront, February 9, 2022.doi: 10.1377/forefront.20220207.574426