



American Academy of Hospice and Palliative Medicine

Testimony for the Record  
Before the House Committee on Appropriations, Labor, Health and Human Services,  
Education, and Related Agencies Subcommittee  
*Public Witness Hearing*  
Thursday, March 23, 2023

Chairman Aderholt, Ranking Member DeLauro, and members of the Subcommittee, the American Academy of Hospice and Palliative Medicine (AAHPM or Academy) appreciates the opportunity to provide testimony for the record 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 thank you for including language in the explanatory statement to the *Consolidated Appropriations Act, 2023*, urging the National Institutes of Health (NIH) to ensure that palliative care is integrated into all areas of research across NIH and requesting an update on plans for this effort in the fiscal year (FY) 2024 Congressional Justification. **In FY 2024, AAHPM requests \$20 million for the National Institutes of Health to advance a trans-NIH effort to expand and intensify the strategic coordination of palliative care research efforts as well as identify future research topics and questions that pertain to palliative care.** This level of funding would supplement existing funding and support a coordinating center to convene subject matter experts from relevant Institutes, Centers, and Offices (ICOs); provide career development grants for early-stage investigators; and facilitate various NIH-supported core facilities that help connect scientists with needed tools and expertise.

AAHPM is the professional organization for physicians specializing in Hospice and Palliative Medicine. Our 5,600 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.<sup>1</sup>) 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.

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.**<sup>2</sup> 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.<sup>3,4</sup> 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.<sup>5</sup>

#### **FY 2024 APPROPRIATIONS REQUEST**

Research related to palliative care and serious illness crosses nearly every Institute, Center, and Office at NIH, but also poses challenges because it does not fit neatly within a single ICO. The Academy appreciates that Congress included report language in the joint explanatory statement of the FY 2023 funding bill and previously encouraged palliative care research in the FY 2011 and FY 2019 reports. We are optimistic that the recent language will help improve coordination and expand activities related to palliative care research across NIH. Already, NIH has responded to the appropriations language by including a “summary of ongoing activities” in the FY 2024 Congressional Justification (CJ). The CJ highlights multiple ways that NIH is accelerating research related to palliative care and serious illness, such as by convening a workshop with healthcare providers, researchers, and certain policymakers in December 2022 to identify research opportunities related to care for people with advanced heart failure.

Most importantly, the CJ also describes how the National Institute on Aging (NIA) is “leading efforts to convene subject matter experts” from nearly ten NIH Institutes to “expand and intensify strategic coordination of palliative care research efforts as well as identify future research topics and questions that pertain to palliative care.” AAHPM is encouraged by the inclusion of this language and hopes the Subcommittee will support NIH’s efforts in this space.

**AAHPM requests that the Subcommittee include \$20 million in the FY 2024 Labor, Health and Human Services, Education, and Related Agencies Subcommittee funding bill to advance a trans-NIH effort to expand and intensify the strategic coordination of palliative care research efforts as well as identify future research topics and questions that pertain to palliative care.** This level of funding could support a coordinating center to convene subject matter experts from relevant ICOs; provide career development grants for early-stage investigators; and facilitate various NIH-supported core facilities that help connect scientists with needed tools and expertise.

The Academy thanks the Subcommittee for previous report language and requests funding in FY 2024 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.

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## REFERENCES

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<sup>1</sup> Kelley AS, Bollens-Lund E. Identifying the Population with Serious Illness: The "Denominator" Challenge. *J Palliat Med.* 2018 Mar;21(S2):S7-S16. doi: 10.1089/jpm.2017.0548. Epub 2017 Nov 10. PMID: 29125784; PMCID: PMC5756466.

<sup>2</sup> “The Evidence for High-Quality Palliative Care.” American Academy of Hospice and Palliative Medicine. Accessed February 15, 2023. [https://aahpm.org/uploads/advocacy/The\\_Evidence\\_for\\_High-Quality\\_Palliative\\_Care.pdf](https://aahpm.org/uploads/advocacy/The_Evidence_for_High-Quality_Palliative_Care.pdf)

<sup>3</sup> 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.

<sup>4</sup> 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

<sup>5</sup> “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