ADVOCATING TEAM CARE FOR OLDER ADULTS

Eldercare Workforce Alliance

ISSUE BRIEF

End-of-Life Care: Preparing the Eldercare Workforce

As more of us live longer, our country faces new challenges and opportunities. By 2030, for example, more than 70 million of us will be over age 65,[i] and approaching the time of life when we are most likely to need end-of-life care.[ii] To meet the needs of our aging population, the Eldercare Workforce Alliance (EWA) advocates for public policies that support programs such as the Geriatrics Workforce Enhancement Program (GWEP). GWEP, the only federal program designed to increase the number of providers in a variety of disciplines with the education and training to care for older adults, currently trains health care professionals and students, direct care workers, and family caregivers in 29 states. EWA has also advocated for public policies that support family caregivers and has been a leading advocate for wages and training for the direct care workforce. The Alliance strives to ensure that our health care workforce is an *eldercare* workforce with the skills and knowledge needed to support all of us in remaining active in our homes and communities.

EWA believes that realizing this goal of an eldercare workforce also means ensuring that the workforce is prepared to support all of us at the end of life. Similar to health providers specializing in geriatrics and gerontology, providers specializing in palliative care (care that optimizes quality of life by preventing and relieving suffering associated with a serious illness)[iii] remain in short supply.[iv,v,vi] This issue brief presents some of the ways geriatrics, gerontological, and palliative care training can strengthen the entire workforce's capacity to provide high-quality end-of-life care for older adults.

The Eldercare Workforce and End-of-Life Care

Family Caregivers

Some 43.5 million Americans are family caregivers[vii]. And, we know that our roles as caregivers expand significantly as we and our family members age. These roles can range from helping with activities of daily living (such as cleaning, cooking, shopping, dressing, and bathing) to more complex tasks such as managing finances, managing prescription drug regimens, and providing medical care. At the end of life, the physical and emotional support family caregivers provide increases considerably. New responsibilities can include learning how to identify and relieve symptoms associated with suffering; supporting older adults in making difficult decisions about transitions to alternate care settings or to hospice; making healthcare decisions for older adults who may be unable or uncomfortable doing so on their own; and coordinating communication with other members of the health care team. Without adequate support for family caregivers, these responsibilities can lead to high levels of depression and stress, especially in relation to end-of-life decision-making.[viii] **Investing in resources to support family caregivers will help all of us to support our family members as they age and at the end of life.**

Health Care Professionals

Geriatrics and gerontological health professionals are experts with extensive training in the care we all need as we age. Such training includes an intensive focus on the unique health conditions many older adults face and on strategies and resources that enable older adults to live with these conditions. Experts in older adult health care have long worked in interdisciplinary teams, recognizing that each discipline has a unique skill set essential to coordinated, person-centered care. Team members include pharmacists, physicians, psychiatrists, psychologists, social workers, spiritual care professionals, occupational and physical therapists, and advanced practice nurses, incorporating other professionals as needed. The eldercare team works to maximize function, health,

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independence, and well-being for older adults, modifying care plans over time to meet the care goals of an older person. Yet, these geriatrics and gerontological health professionals remain in short supply, and these workforce vacancies impede end-of-life care.

Fast Facts

- Although 70% of Americans want to die at home, only 30% actually do.[ix]
- Family caregivers play multifaceted roles in caring for older adults at the end of life, yet they often lack the support they need to fulfill these roles.[x,xi]
- Across disciplines, the availability of health care workers with geriatrics and gerontological expertise is insufficient to meet the need for care.[xii]
- Because the number of health care workers (across disciplines) who specialize in hospice and palliative care is small, the need for palliative care must also be met through other specialties and in primary care settings.[xiii]

Health professionals specializing in palliative care also receive extensive training in communicating with individuals about goals of care, in identifying and responding to symptoms, and in coordinating care across settings at the end of life. Similar to geriatrics and gerontological health professionals, palliative care professionals focus on team-based collaboration. Palliative care has been provided for decades within hospice programs. Over the past decade, the number of palliative care teams that are based in acute care hospitals has grown, and the Joint Commission has established a certification program that recognizes hospitals for excellence in providing palliative care. As palliative care has matured, there has been a movement to bring these services to other settings, including home-based primary care and long-term care.[xiv] As with geriatrics and gerontological health professionals, however, there are too few palliative care health professionals, which means many positions go unfilled.

Increasing the number of health care professionals specializing in geriatrics, gerontology, and palliative care will improve health care delivery as we age and at the end of life. Ensuring that the entire health care workforce understands the basic principles of these specialties will also improve care.

Direct Care Workers

Direct care workers—including home health aides, personal care assistants, and certified nursing assistants—provide the majority of paid, hands-on care for older adults across settings. Direct care workers' many responsibilities may include provide assistance with activities of daily living, arranging health care appointments, and providing respite care to family caregivers. Direct care workers often receive inadequate training and poor compensation, and they often lack career advancement opportunities. Caring for an older adult at the end of life brings additional challenges, given the highly personal, hands-on nature of this work. **Providing opportunities for advanced training and improving working conditions will enhance the ability of direct care workers to provide high-quality care as we age and at the end of life.**

Importance of Advance Care Planning

Many members of the health care team play integral roles in discussing goals of care with older adults. These conversations take place in a variety of settings, often in the context of a bundled payment system and sometimes without third-party reimbursement. In 2016 Medicare began to reimburse certain health care providers for discussions with beneficiaries about advance care planning,[xv] and data indicate that beneficiaries are interested in having these conversations.[xvi] Advance care planning conversations provide an opportunity for older people to discuss their goals for care at the end of life. Documentation of an older person's choices in advance directives (legal documents outlining health care choices) and in the health care record is an important component of these conversations. However, many older persons still do not discuss their wishes with friends and family members, nor do they complete advance directives.[xvii] In the absence of such advance care planning, family members and health care professionals may have to make end-of-life decisions without knowledge of an older person's care

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preferences. In these situations, the decisions made may not be congruent with the care an older person would have chosen.

Communication about values, goals, and care choices through an ongoing process of advance care planning is essential to high-quality care as we age and at the end of life.

EWA Recommendations

• Reauthorize and expand the Geriatrics Workforce Enhancement Program (GWEP) under Titles VII and VIII of the Public Health Service Act by passing the Geriatrics Workforce and Caregiver Enhancement Act (H.R. 3713) and by appropriating $51 million for GWEP in fiscal year 2018.

• Integrate geriatrics, gerontology, and palliative care curricula into academic programs for health care professionals; prioritize geriatrics, gerontology, and palliative care competencies within such programs and within continuing education programs.

• Develop specialized training programs in geriatrics, gerontology, and palliative care for direct care workers.[xviii]

• Increase Medicaid reimbursement rates to direct care workers to enhance retention in the eldercare workforce; avoid reductions in Medicaid spending, including block grants and per-capita caps, that could decrease older adults' access to end-of-life care in home and community-based settings.[xix]

• Increase access to resources that support older adults and family caregivers in making and implementing decisions about end-of-life care.

• Increase funding for the National Family Caregiver Support Program, Native American Caregiver Support Program, Alzheimer's Disease Supportive Services Program, and Lifespan Respite Care Program to enhance supports available to family caregivers of older adults at the end of life.[xx,xxi]

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[i] IOM (Institute of Medicine), 2008, *Retooling for an aging America: Building the health care workforce.* Washington, DC: The National Academies Press, 1.

[ii] IOM, 2014, *Dying in America: Improving quality and honoring individual preferences at the end of life.* Washington, DC: The National Academies Press, 25.

[iii] Please refer to the National Consensus Project's *Clinical Practice Guidelines for Quality Palliative Care* (3rd ed., 2014, p. 9) for a comprehensive definition of palliative care. https://www.nationalcoalitionhpc.org/ncp-guidelines-2013/

[iv] "Recommendations to the Administration for End-of-Life Care," letter to Tom Price, MD and David Shulkin, MD, February 21, 2017, Pew Charitable Trusts, 6, http://www.pewtrusts.org/~/media/assets/2017/02/recommendations-to-the-administration.pdf

[v] IOM, *Dying in America,* 102.

[vi] IOM, *Retooling*, 217.

[vii] AARP, 2015, *Caregiving in the U.S.* Washington, DC: AARP Public Policy Institute, 6.

[viii] Katherine A. Ornstein et al., "A National Profile of End-of-Life Caregiving in the United States,"Health Affairs 36, no. 7 (July 2017): 1184.

[ix] "Recommendations to the Administration for End-of-Life Care," Pew Charitable Trusts, 7.

[x] National Academies of Science, Engineering, and Medicine. (2016). *Families caring for an aging America*. Washington, DC: The National Academies Press, 79.

[xi] IOM, *Dying in America*, 94.

[xii] IOM, *Retooling,* 1.

[xiii] IOM, *Dying in America*, 2.

[xiv] The National Consensus Project for Quality Palliative Care is revising its *Clinical Practice Guidelines for Quality Palliative Care* to reflect, in a more explicit manner, the provision of palliative care in community-based settings. Visit https://www.nationalcoalitionhpc.org/ncp-guidelines-2018/ for additional information.

[xv] Centers for Medicare & Medicaid Services. (2016). Advance care planning [Fact sheet], https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/AdvanceCarePlanning.pdf

[xvi] JoNel Aleccia, "End-of-life care: More than 500,000 chat on Medicare's dime," USA Today (August 14, 2017), https://www.usatoday.com/story/news/health/2017/08/14/end-of-life-advice-more-than-500-000-chat-medicares-dime/550629001/

[xvii] IOM, *Dying in America*, 18.

[xviii] *ADVANCED DIRECT CARE WORKER: A Role to Improve Quality and Efficiency of Care for Older Adults and Strengthen Career Ladders for Home Care Workers,* issue brief, Eldercare Workforce Alliance, September 2014, 5, https://eldercareworkforce.org/files/EWA_Advanced_DCW_Issue_Brief-pub2014.pdf.

[xix] Eldercare Workforce Alliance. (2017). *Preserve Medicaid for our nation's older adults and those who care for them.* https://eldercareworkforce.org/files/FY18_EWA_Appropriations_FINAL_Update.pdf

[xx] Eldercare Workforce Alliance. (2017). *Family caregivers: The backbone of our eldercare system.* https://eldercareworkforce.org/research/issue-briefs/research:04-14-2017-family-caregivers-the-backbone-of-our-eldercare-system/

[xxi] Eldercare Workforce Alliance. (2017). *FY18 eldercare workforce appropriations requests.* https://eldercareworkforce.org/files/FY18_EWA_Appropriations_FINAL_Update.pdf

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