PATIENT
QUALITY OF LIFE
COALITION

March 1, 2019

The Honorable Lamar Alexander
Chairman
U.S. Senate Committee on Health, Education,
Labor, and Pensions
455 Dirksen Senate Office Building
Washington, D.C. 20510

Re: Response to Chairman Alexander and the Senate Committee on Health, Education, Labor and Pensions (HELP) Request for Comments

Dear Chairman Alexander:

We are writing collectively as members of the Patient Quality of Life Coalition (PQLC), a group of over 40 organizations dedicated to advancing the interests of patients and families facing serious illness, with the overarching goal of providing these individuals with greater access to palliative care services. Members represent patients, health professionals, and health care systems. The Coalition commends the Senate Health Education Labor and Pensions (HELP) Committee's effort to seek multi-stakeholder input on ways to help address America's rising health care costs. As the HELP Committee moves towards enacting legislation to address rising health care costs, we encourage you to include policies that would expand access to palliative care services.

Palliative care is specialized care for people living with serious illnesses.[1] It focuses on providing patients with relief from the symptoms and stress of a serious illness. Palliative care is provided by a team of doctors, nurses, social workers, physician assistants, nurse practitioners and specialists working together with a patient's other healthcare providers to provide an extra layer of support. Palliative care is appropriate at any age and any stage in a serious illness (ideally made available to patients upon their diagnosis) and can be provided along with curative treatment.[2] By relieving complex pain and symptoms, palliative care improves a patients' ability to tolerate medical treatments and carry on with daily life. It also empowers patients to play a greater role in their own care by facilitating communication between patients, caregivers, and providers across the care continuum.

Studies show that without palliative care, patients with serious illnesses and their families receive poor-quality care that is characterized by inadequately treated symptoms, fragmented services, lack of psycho-social support, poor communication with health care providers, resulting in enormous strain on family members or other caregivers.[3,4] In every setting in which it has been tested, including hospitals, clinics, and at home, palliative care improves care quality for the sickest and most vulnerable patients

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[1] "Serious illness" is defined as a health condition that carries a high risk of mortality and either negatively impacts a person's daily function or quality of life, or excessively strains their caregivers. See Kelley AS, Bollen-Lunds E. Identifying the Population with Serious Illness: The "Denominator" Challenge. J Palliat Med. 2017 Nov 10. doi: 10.1089/jpm.2017.0548.

[2] Smith, TJ, Temin S, Alesi ER, Abernathy AP, Balboni TA, Basch EM, Ferrell BR, Loscalzo M, Meier DE, Paice JA, Peppercorn JM, Somerfield M, Stovall E, Von Roenn JH. American Society of Clinical Oncology Provisional Clinical Opinion: The Integration of Palliative Care Into Standard Oncology Care. J Clinical Oncol 2012; 30: 880-887.

[3] Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V. Family perspectives on end-of-life care at the last place of care. JAMA. 2004 Jan 7; 291(1):88-93.

[4] Meier DE. Increased Access to Palliative Care and Hospice Services: Opportunities to Improve Value in Health Care. The Milbank Quarterly. 2011;89(3):343-380. doi:10.1111/j.1468-0009.2011.00632.x.

across all diseases.[5] By focusing on priorities that matter most to patients and their families, palliative care has been shown to improve both quality of care and quality of life during and after treatment.[6,7] In one study, patients with metastatic non-small-cell lung cancer who received palliative care services shortly after diagnosis even lived longer than those who did not receive palliative care.[8]

Some Medicare Advantage plans have begun to provide palliative care services to their enrollees. One successful model is Aetna's Compassionate Care Program, which uses care managers who provide a comprehensive assessment of the patient's needs by telephone and consult with the patient, physician, and the patient's family. These care managers provide education and support, give assistance with pain medications and psychosocial needs, and help ensure that advance directives are in place and complied with.[9]

The use of palliative care services has been shown to reduce costs. Better care for high-risk, high cost patients leads to reduction in reliance on 911 calls, emergency department visits, hospital admissions and readmissions and leads to consistent and substantial reductions in associated health care spending. One study found that the receipt of a palliative care consultation within two days of admission was associated with 22 percent lower costs for patients with certain comorbid conditions.[10] Palliative care results in fewer crises, reducing hospital utilization and resulting in overall cost savings.[11] Another study focused on nurse-led, palliative care-focused interventions focused on physical, psychosocial and care coordination provided in consultation with oncology services for patients with advanced cancer in a rural area. The study concluded that those receiving the palliative care services had higher quality of life and mood scores compared to those receiving oncology services alone.[12]

Yet, despite the demonstrated benefits of palliative care, there remain millions of Americans who do not access such services. Many of these people are included in the five percent of patients who account for approximately 60 percent of all health care spending – those with multiple chronic conditions and functional limitations who have persistent high costs.[13]

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[5] Smith S, Brick A, O'Hara S, Normand C. Evidence on the cost and cost-effectiveness of palliative care: a literature review. Palliat Med. 2014 Feb;28(2):130-50.

[6] Delgado-Guay MO, et al. Symptom distress, interventions, and outcomes of intensive care unit cancer patients referred to a palliative care consult team, 115(2) Cancer 437-45 (2009).

[7] Casarett D, et al., Do palliative consultations improve patient outcomes? 56 J Am Geriatric Soc'y 593, 597-98 (2008).

[8] Temel JS, Greer JA, Muzikansky A, et al. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med. 2010;363:733-742.

[9] Krakauer R, Spettell CM, Reisman L, Wade MJ. Opportunities to improve the quality of care for advanced illness. *Health Affairs* 28(5)1357-1359 (2009).

[10] May P, et al. Palliative Care Teams' Cost-Saving Effect Is Larger For Cancer Patients With Higher Numbers Of Comorbidities. Health Affairs. January 2016.

[11] Agency for Healthcare Research and Quality: System-integrated program coordinates care for people with advanced illness, leading to greater use of hospice services, lower utilization and costs, and high satisfaction. www.innovations.ahrq.gov/content.aspx?id=3370.

[12] Bakitas M, Doyle Lyons K, Hegel MT, Balan S, Brokaw FC, Seville J, Hull JG, Li Z, Tosteson TD, Byock IR, Ahles TA. Effects of a palliative care intervention on clinical outcomes in patients with advanced cancer. *JAMA* 2009;302(7):741-749.

[13] IOM (Institute of Medicine). 2014. Dying in America: Improving quality and honoring individual preferences near the end of life. Washington, DC: The National Academies Press.

The Palliative Care and Hospice Education and Training Act (PCHETA)

The PQLC supports the Palliative Care and Hospice Education and Training Act (PCHETA), which would help to ensure that more individuals have access to palliative care services by addressing:

- The need to train more physicians, nurses, social workers, and other health professionals in the medical subspecialty of palliative care;
- The need to educate the public and providers about the availability of palliative care; and
- The need for a greater investment in evidence based research specific to palliative care, and symptom management.

By expanding the palliative care workforce, awareness, and research, this bipartisan legislation will improve quality of care and quality of life for millions of patients living with serious or life-threatening illness and their family/caregivers.

PCHETA passed unanimously in the House of Representatives last Congress and had strong bi-partisan support in the Senate. The House bill, H.R. 647, was recently re-introduced and the Senate bill is expected to be re-introduced shortly. We urge the Committee to consider this legislation as you develop policy proposals to address health care costs.

Conclusion

On behalf of the Patient Quality of Life Coalition, we thank you for the opportunity to submit policy ideas and proposals to the Senate HELP Committee. As the Committee examines ways to help address America's rising health care costs, we welcome the opportunity to discuss policy proposals that would provide patients greater access to palliative care. If you have any questions, please contact Keysha Brooks-Coley, Chair of the Patient Quality of Life Coalition, at 202-661-5720 or Keysha.Brooks-Coley@cancer.org.

Sincerely,

Alzheimer's Association
Alzheimer's Impact Movement
American Academy of Hospice and Palliative Medicine
American Cancer Society Cancer Action Network
American Heart Association
American Society of Clinical Oncology
Association of Oncology Social Work
Association of Pediatric Hematology/Oncology Nurses
CSU Institute for Palliative Care
Catholic Health Association of the United States
Cancer Support Community
Center to Advance Palliative Care
Children's National Medical Center
Coalition for Compassionate Care of California
Hospice and Palliative Nurses Association

Leukemia & Lymphoma Society
Lung Cancer Alliance
Motion Picture & Television Fund
National Alliance for Caregiving
National Brain Tumor Society
National Coalition for Hospice and Palliative Care
National Hospice and Palliative Care Organization
National Palliative Care Research Center
National Patient Advocate Foundation
Oncology Nursing Society
ResolutionCare Network
Pediatric Palliative Care Coalition
Physician Assistants in Hospice and Palliative Medicine
Prevent Cancer Foundation
St. Baldrick's Foundation
Supportive Care Coalition
Trinity Health