

Updated Testimony on House Bill 2031

Senate Committee on Public Health and Welfare

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Chairwoman Schmidt and Members of the committee, thank you for the opportunity to provide an update on HB 2031. HB 2031 establishes within the Kansas Department of Health and Environment (KDHE) a palliative care education program and advisory council on palliative care and quality of life. The purpose of the Palliative Care and Quality of Life Interdisciplinary Advisory Council is to develop recommendations and advise KDHE on:

- 1) Establishment, operation and evaluation of palliative care initiatives in Kansas; and
- 2) Effectiveness of the Palliative Care Consumer and Professional Information and Education Program which will make available information and education about palliative care to the public, health care providers, and health care facilities.

Palliative care addresses the symptoms and stress of serious illnesses to help patients feel more comfortable and can include a focus on complex pain and symptom management and interventions to improve the quality of life for children and adults with life-limiting conditions and their families or caregivers. Teams of doctors, nurses, and other specialists with palliative care training work with patients' doctors to provide palliative care for patients at any age and at any stage of a serious illness. In contrast to hospice care, palliative care can be provided along with curative treatment.¹

Provision of palliative care has been found to substantially reduce health care costs among cancer patients by 22 – 32%,³ with the greater savings occurring among patients with higher numbers of co-existing medical conditions. Other studies found cost savings up to 24% when palliative care was offered within two days of hospital admission of patients with advanced cancer⁴ and savings in hospital costs when palliative care was received by patients enrolled in Medicaid.⁵

Furthermore, in 2016 the Kansas Behavioral Risk Factor Surveillance system collected information about palliative care among Kansas adults aged 18 years and older:

- 3.3 percent of Kansas adults aged 18 years and older have received palliative care for a severe and chronic illness such as: back-related conditions, cancer, congestive heart failure, mental illness, arthritis and other conditions.⁶
- Among Kansas adults who have received palliative care, 72.0 percent experienced pain from the chronic condition or their treatment. Almost all of those who experienced pain (95.1 percent) were prescribed medications to control the pain by their palliative care team.⁶

- A majority of Kansas adults who received palliative care (80.2 percent) said that the information they received, from the palliative care team, about how to handle stress, depression or problems with emotion was good, very good or excellent. 82.2 percent rated the emotional support they received from their palliative care team as good, very good or excellent.⁶

Current KDHE activities around palliative care are focused on professional education, data collection and analysis related to quality of life and disparities. The scope of work is limited to cancer due to minimal grant funding available. The Bureau of Health Promotion leverages resources through the Kansas Cancer Partnership to support End of Life Nursing Education Consortium (ELNEC) training in person and via video with facilitators across Kansas to increase rural access to palliative care training and patient access. Plans include further expansion of this training into rural areas.

HB 2031 substantially expands KDHE's focus on palliative care activities and exceeds the scope of the current grant and available funding. This bill requires KDHE to establish a program for all palliative care needs including a much broader range of serious illnesses and additional populations. In the US annually, about 500,000 children experience life-limiting conditions expected to eventually lead to premature death.⁷ While the life expectancy may be shorter, children with these conditions are living longer, resulting in a greater need for wrap around services and supports. This often can include pediatric palliative care in conjunction with curative or life-prolonging treatments.⁷

A priority population in need of palliative care includes children and youth with special health care needs. The *National Standards for Systems of Care for Children and Youth with Special Health Care Needs Version 2.0* address palliative and hospice care, providing guidance to states on two key system standards. The first standard is co-occurring curative and palliative care services. The second standard is care that uses a family-centered model of care and provides families access to psychosocial screening and referrals. Additionally, four foundational standards are defined, which align with the National Hospice and Palliative Care Organization Guiding Principles for Pediatric Palliative Care and Hospice. These foundational standards are related to family-centered care, culturally-competent service delivery, insurance coverage, and evidence-based care provision.

Although benefits of palliative care related to quality of life are well-documented, KDHE respectfully notes the following concerns with the bill.

- There is no provision for needed resources to support a new Palliative Care Consumer and Professional Education Program.
- Passage of the bill would require additional staff capacity to implement and coordinate the program, including education, as well as convene and facilitate the required advisory council.
- Additional resources would be needed for evaluation of initiatives and outcomes, including data collection and analysis.
- Additional resources would be needed for expenses related to the 13-member advisory council designed to maximize the effectiveness of palliative care initiatives in the state and ensure accurate and comprehensive information is available.

Thank you for the opportunity to appear before you. I will now stand for questions.

Sources:

¹What is Palliative Care? Center to Advance Palliative Care (CAPC). Accessed 1/17/17. <https://getpalliativecare.org/about/>

²IOM (Institute of Medicine). 2015. *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies Press.

³Palliative Care Teams' Cost-Saving Effect is Larger for Cancer Patients with Higher Numbers of comorbidities. May, P., Garrido, M.M., Cassel, J. B., Kelley, A.S., Meier, D.E., Normand, C, Stefanis, L. Smith, T.J. & Morrison, R.S. *Health Aff* January 2016 vol. 35 no. 1 44-53. doi: 10.1377/hlthaff.2015.0752

⁴Prospective Cohort Study of Hospital Palliative Care Teams for Inpatients with Advanced Cancer: Earlier Consultation is Associated with Larger Cost-Saving Effect. [J Clin Oncol](#). 2015 Sep 1;33(25):2745-52. doi: 10.1200/JCO.2014.60.2334. Epub 2015 Jun 8.

⁵Palliative Care Consultation Teams Cut Hospital Costs for Medicaid Beneficiaries. Morrison, R.S., Dietrich, J., Ladwig, S., Quill, T., Sacco, J., Tangeman, J., & Meier, D.E. *Health Affairs* 30, NO. 3 (2011): 454–463 2011. doi: 10.1377/hlthaff.2010.0929.

⁶2016 Kansas Behavioral Risk Factor Surveillance System, Bureau of Health Promotion, Kansas Department of Health and Environment.

⁷*Financing Pediatric Palliative and Hospice Care Programs*, a publication of the Catalyst Center: Improving Financing of Care for Children and Youth with Special Health Care Needs, April, 2011.