

Policy Issue: Adopt statutory language for supportive palliative care

A majority of people with a serious illness wish to spend as much time as possible in a non-hospital setting, among loved ones, free from high symptom burden (pain, etc.), and not being a burden to their family. Achieving these outcomes will require increased awareness among both health care professionals and patients that supportive palliative care is not reserved for the end of life. While hospice palliative care (HPC) addresses the terminal stage of serious illness, supportive palliative care (SPC) can be beneficial regardless of prognosis, be combined with treatments to cure illness or extend life, and is most effective if started in the early stages of disease.¹ To help get these important specialty services to Texans when most needed, Texas law should be clear about the two distinct specialty services for both SPC and HPC.

Recommendation

Texas should adopt statutory language for SPC as distinct from HPC. The SPC language should be written as a new chapter in the Health and Safety Code, not appended to an existing chapter. Once established, Texas should leverage any new statutory language through collaborative efforts with health plans and other stakeholders to develop a value-based SPC pilot focused on the most vulnerable Texans with serious illness.

Discussion

To operationalize this recommendation, the PCIAC suggests the 86th Texas Legislature add the following language to the Texas Health and Safety Code:

Definition for Supportive Palliative Care

"Supportive Palliative Care (SPC)" means patient and family-centered health care that optimizes quality of life by:

¹ A. Sinclair and D. Meier, "How States Can Expand Access to Palliative Care," Health Affairs Blog, January 30, 2017, <http://healthaffairs.org/blog/2017/01/30/how-states-can-expand-access-to-palliative-care/> (accessed February 16, 2017).

1. *anticipating;*
2. *preventing, and*
3. *treating a patient's suffering;*

Without regard to the patient's age or stage of serious (high-risk mortality and/or life-limiting) illness.

Effective and comprehensive SPC:

1. *addresses the physical, intellectual, emotional, cultural, social, and spiritual needs of the patient;*
2. *facilitates patient autonomy; and*
3. *ensures that the patient receives relevant information to support the informed consent decision making process.*

SPC:

1. *is not based on prognosis; and*
2. *does not require the patient to decline attempts of disease modifying therapy.*

An effective, comprehensive interdisciplinary Supportive Palliative Care (SPC) healthcare team includes at least:

1. *one (1) prescribing healthcare clinician;*
2. *one (1) APRN (Nurse Practitioner)*
3. *one (1) registered nurse;*
4. *one (1) social worker;*
5. *one (1) chaplain; and*
6. *any other person(s)/professional(s) who can enhance the quality of life for both the SPC patient and his/her family. Examples include Physical/Speech/Occupational Therapists, Child Life Specialists, Nutritionists, Music Therapists, Art Therapists, Psychologists, specially trained volunteers and more.*

SPC is a distinct and different term from “hospice” care as defined in Chapter 142 Home and Community Support Services Agencies in the Texas Health and Safety Code.

SPC Standards of Care

To support this statutory definition, industry and stakeholders should develop minimum expectations and standards of care for SPC services that meet the needs of patients, families, and communities across Texas. The delineated minimal standards of care and quality measures outlined reflect the present gold standard of evidenced based specialty SPC. The current SPC literature review reveals consistently that SPC affords a wealth of benefits to patients and health care professionals with a clear persistent phenomena of positive economic impacts for SPC programs adhering to the gold standard of SPC specialty practice.²

While the Council believes it would be premature to adopt such standards in statute (due to a number of moving variables), the Council does recognize the following criteria as the current evidenced based gold standard of practice that specialty SPC teams and programs should strive to meet:

- 1.** Ideally, SPC services should be medically directed utilizing and implementing an interdisciplinary SPC program to include, at minimum:
 - a.** 24 hours a day /seven days a week response to patient/family crisis; and
 - b.** Services provided across all healthcare settings, for example: home, personal care home, long term care facilities (residential care/skill need care), long term acute care, acute rehab unit, outpatient clinic, and acute inpatient hospital.
 - c.** SPC services do not include hospice care benefit services as defined by the Texas Health and Safety Code.

² Morrison, RS, Penrod JD, et al. *Arch Intern Med.* 2008; 168(16):1783-1790; Penrod JD, Deb P, et al. *J Palliat Med.* 2010 Aug;13(8):973-79; Morrison RS, Dietrich J, et al. *Health Affairs.* 2011 Mar;30(3):454-63; McCarthy I, Philastre MR, Fine RL, et al. *Health Services Research.* 2015; 50(1): 217-236; May P, Garrido MM, Cassell JB, et al. *J Clin Oncol.* 2015, 33(25): 2745-2752; Sweeney L, Halpert A, et al. *Am J Manag Care.* 2007 Feb;13(2):84-92.

2. If a licensed healthcare entity (licensee) provides supportive palliative care, the licensee shall have written policies and procedures for the comprehensive delivery of SPC services including, at **minimum, but not limited to, the:**
 - a. assessment of the patient's pain and other distressing symptoms;
 - b. management of the patient's pain and other distressing symptoms;
 - c. goals of care;
 - d. advance care planning;
 - e. provision of, or access to, services to meet the psychosocial and spiritual needs of the patient and family;
 - f. provision of, or access to, a support system to help the family cope during the patient's illness; and
 - g. resources or referrals for bereavement support for the SPC patient's family.

Background

While hospice is currently defined in Texas statute, the lack of a standardized and recognized definition for SPC prevents individuals from accessing palliative care services early in the course of serious illness when it can be most effective. This lack of a clear definition for SPC to distinguish it from HPC is the starting point for a cascading set of risks that can result in inferior care for many Texas patients and families. These risks include:

- Patients, families, and clinicians not fully aware of the significant differences and benefits of each service line, leading to a lack of true informed consent for treatment in the context of patient-centered goals of care;
- Limitation on the availability of formal health care education opportunities for providers on the differences between SPC and HPC;
- Reduced access to and utilization of palliative care services, particularly early in the progression of serious disease; and
- Patients at the brink of death in the hospital as a result of non-beneficial and/or non-desired medical care as patients, their families, and medical teams endure high symptom burden and emotional and ethical distress.

Healthcare environments across settings (outpatient clinic, acute care hospital, long term care, rehabs, homes, assisted livings, personal care homes, long term acute care) have documented medical team angst and distress, delays in healthcare causing increased financial cost, and poor communication/continuity of care. The confusion about the definitions and benefits of SPC and HPC only add to these significant health care strains. Defining SPC is the first major step to garnering public and health care professional awareness and decreasing confusion. Once confusion is minimized, further funding and education opportunities will emerge to foster research and pilot programs to benefit those in need of SPC.

Defining SPC across the nation at the state policy level is an emerging phenomenon being pursued with excitement and urgency. The effort to distinguish SPC from HPC is a response to escalating healthcare costs and stakeholder demand for improved access to high quality services across the life continuum. Defining SPC at the state level is the first in a series of progressive steps toward improving access to high quality and affordable services for both SPC and HPC. States that succeed at this first step go on to provide creative and innovative state-specific SPC and HPC benefit service lines.

Several states - including California, Colorado, Maryland, North Carolina, and Florida - are actively engaging stakeholders and legislators in new, modern, and relevant initiatives for SPC and HPC. State initiatives include defining SPC as distinct from HPC and the creation of state-wide palliative care advisory councils. Defining both SPC and HPC will foster movement towards new recognized PC benefit lines specific to meet the needs of all Texans.

A landmark report from the Health and Medicine Division of the National Academy of Medicine (NAM) [previously the Institute of Medicine (IOM)] described the lack of quality health care for patients dying in America. NAM states, "One of the greatest remaining challenges is the need for better understanding of the role of palliative care among both the public and professionals across the continuum of care so that hospice and palliative

care can achieve their full potential for patients and their families”.³ The clear and concise acknowledgement by NAM of meaningful, but different health care roles for SPC and HPC adds evidence in support of further specialty efforts and health policy reforms to define SPC as distinct from HPC in formal legislation.

Without clarifying legislative and educational efforts, the important role of SPC is likely to remain conflated with HPC in the minds of both health professionals and patients. According to Parikh, et al., SPC “suffers” from an identity crisis unlike HPC.⁴ This seminal article provided the clinical, educational, financial, and political case for defining SPC and improving consumer and clinician understanding of how to access and utilize SPC when HPC is not appropriate. As a result, the American Cancer Society (ACS) encourages cancer care clinicians to adhere to recently updated American Society of Clinical Oncology (ASCO) guidelines, which recommends early SPC for all metastatic cancer patients within eight weeks of diagnosis, a standard Texas will be challenged to meet even in its largest SPC programs.

In California, an intensive outpatient palliative care pilot -- Partners in Palliative Care -- is helping to pave the way for the development of innovative and cost effective service lines that can deliver SPC services to more people early in the progression of serious disease. An evaluation of the program found it addressed a significant need for outpatient palliative care services in the state. Financially, the pilot was estimated to save \$3 in hospital costs for every \$1 spent on palliative care services.⁵ The program also received the highest marks in levels of patient and family satisfaction, with up to 95% of participants reporting that they always received the best possible care from their palliative care team.⁶ The Council believes this type

³ (NAM, 2014, p.29)

⁴ Parikh, et al. (2013) NEJM

⁵ Partners in Palliative Care
http://www.partnershiphp.org/Providers/Quality/Documents/Strategic%20Initiatives%202017/PHC%20Palliative%20Care%20Program%20Summary_3_23_17.pdf

⁶ Ibid.

of data suggests the possibility of significant benefits to patients and families but also to both government (Medicaid) and non-government payers.

DRAFT