



**Texas Palliative Care
Interdisciplinary
Advisory Council
Recommendations to
the 86th Texas
Legislature**

**As Required by
H.B. 1874, 84th Legislature,
Regular Session, 2015**

November 2018

About This Report

This report was prepared by members of the Texas Palliative Care Interdisciplinary Advisory Council. The opinions and recommendations expressed in this report are the members' own and do not reflect the views of the Texas Health and Human Services Commission Executive Council or the Texas Health and Human Services Commission.

The information contained in this document was discussed and voted upon at regularly scheduled meetings in accordance with the Texas Open Meetings Act. Information about these meetings is available at <https://hhs.texas.gov/about-hhs/leadership/advisory-committees/palliative-care-interdisciplinary-advisory-council>.

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1. Letter from Chair

The 2015 84th Texas Legislature established the Health and Human Services Commission's Palliative Care Interdisciplinary Advisory Council (PCIAC) via HB 1874 (Zerwas), charging the Council with assessing the availability of palliative care in Texas along with promoting professional and public education about palliative care in order to enhance Texans' access to high-quality and continuously improving palliative care services.

To those ends, the Council published its first report to the Commission, the Governor, and the Legislature in November 2016; and now provides this second biennial report. The initial report offered a number of recommendations that became action items and then accomplishments of the charges.

- Developed and launched the Texas Health and Human Services (HHS) system palliative care website resource for patients, families, and professionals
- Developed and conducted an annual palliative care interdisciplinary continuing professional education event starting in 2017; established a repository of education resources linked within the HHS palliative care website
- Established methods and means to track and report on key measures of palliative care access
- Advanced a statewide, population-based data collection initiative to assess completion of advance care planning documents in Texas
- Elevated the profile of serious illness care as a significant area of opportunity for raising overall healthcare quality in Texas
- Adapted and collaborated with the national Center to Advance Palliative Care to monitor ongoing Texas metrics pertaining to palliative care

Since 2015, Texas has seen substantial growth in numbers of healthcare professionals focusing on palliative care along with increased availability of clinical services for inpatients and outpatients alike. The work of this Council has been integral to the multifaceted enhancement of palliative care in Texas, as we endeavor to advance Texas as a model of excellence. Those efforts are well stated in this report.

A cornerstone concept of the first report was the Council's recommendation to refine the language of palliative care to broaden application beyond end-of-life care. This has spurred favorable statewide discussion among healthcare professionals and has positioned Texas as a leader in this growing national trend.

In our second report, the Council recommends codifying the defining language into law as a prelude to demonstrating the enhanced value-based care that is possible at any stage of serious illness. In addition, continued emphasis on Advance Care Planning is paramount to helping palliative care services meet the individual and personal expressed needs of patients and families.

This second biennial report summarizes efforts and progress over the interim since the initial report, and delineates recommendations for further advancements, including the following policy issues:

- Policy Issue: Adopt Statutory Language for Supportive Palliative Care
- Policy Issue: Prioritize Advance Care Planning
- Policy Issue: Address Palliative Care Provider Shortages
- Policy Issue: Expand Supportive Palliative Care Programs as a Value-Based Model
- Policy Issue: Establish a Statewide Palliative Care Dashboard
- Policy Issue: Seek a Balanced Response to the Opioid Crisis

The Council has invested considerable thought and deliberation into the “Why?” and “How?” of these issues, and those reflections are detailed in the text related to the respective topics. The specified recommendations of the Council offer good faith solutions reflecting multiple stakeholders to help our state move forward toward a goal that all Texas patients and families facing serious illness have the information and opportunity to choose care that fits their individual circumstances and values; and, care that is of the highest possible quality based upon excellent interdisciplinary education and training opportunities. And, finally, we offer thoughtful considerations about appropriate palliative care in the setting of our ongoing national opioid crisis, requiring conscientious efforts by healthcare professionals and systems along with prudent public policy.

The Council offers this report for thoughtful review and reflection, and for sound consideration of the recommendations. Please contact us any time for any further information, explanation, or discussion.

Larry Driver, MD

Larry C. Driver, MD
Chair, Palliative Care Interdisciplinary Advisory Council

2. About the Palliative Care Interdisciplinary Advisory Council

House Bill (H.B.) 1874, 84th Legislature, Regular Session, 2015, established the Palliative Care Interdisciplinary Advisory Council (PCIAC). By rule (Texas Administrative Code §351.827) the Council assesses the availability of patient-centered and family-focused interdisciplinary team-based palliative care in Texas for patients and families facing serious illness. The Council works to ensure that relevant, comprehensive, and accurate information and education about palliative care is available to the public, health care providers, and health care facilities. This includes information and education about complex symptom management, care planning, and coordination needed to address the physical, emotional, social, and spiritual suffering associated with serious illness.

The Palliative Care Council performs the following tasks:

1. Consults with and advises the Health and Human Services Commission (HHSC) on matters related to the establishment, maintenance, operation, and outcome evaluation of the palliative care consumer and professional information and education program established under Texas Health and Safety Code §118.011;
2. Studies and makes recommendations to remove barriers to appropriate palliative care services for patients and families facing serious illness in Texas of any age and at any stage of illness; and
3. Pursues other deliverables consistent with its purpose as requested by the Executive Commissioner or adopted into the work plan or bylaws of the Council.

3. Palliative Care Interdisciplinary Advisory Council Members

The Palliative Care Interdisciplinary Advisory Council consists of 18 members appointed by the Health and Human Services Commission (HHSC) Executive Commissioner who are leaders and experts in their fields, including physicians, nurses, a social worker, a pharmacist, a spiritual professional, and advocates. Larry Driver, M.D. serves as the current chair of the Council. The current vice-chair is Barbara Jones, Ph.D., M.S.W. The Council also includes ex officio, non-voting representation from HHSC.

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4. Executive Summary

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 pain and other distressing symptoms. To help achieve this vision, House Bill 1874 (84th Texas Legislature, Regular Session, 2015) established the Palliative Care Interdisciplinary Advisory Council and the Palliative Care Information and Education Program. Together, the Council and program work to make Texas a national leader for providing appropriate, compassionate, and high quality palliate care to patients and families.

Palliative care is not end of life care. It offers specialized, multi-disciplinary support to relieve a patient's symptoms, pain, and stress at any stage of a life threatening illness. While hospice palliative care helps patients in the terminal stage of serious illness, supportive palliative care is most effective when started early as part of an individual's overall treatment plan. The best available evidence shows that supportive palliative care improves quality of life, reduces patient and caregiver burden, and lowers medical costs.

A check on results three years out from passage of House Bill 1874 sees the state advancing in its efforts to increase access to palliative care. For the first time, the state has launched a central website resource to provide critical information and education to patients, families, and professionals and is monitoring relevant indicators of progress and performance. Awareness of the benefits of palliative care is on the rise as is the number of multi-disciplinary specialty providers, medical fellows, and inpatient palliative care programs. However, even with this initial momentum, substantial gaps in access to palliative care persist. Service levels and professional resources remain below rates found in most other states. Moreover, some Texas communities, such as the Rio Grande Valley, El Paso, and rural areas generally, appear particularly disadvantaged with regard to palliative care infrastructure.

With this background in mind, the Council releases its second biennial report to the Texas Legislature with ideas to improve access to patient-centered and family-focused palliative care. The recommendations that follow (see below), all adopted without a dissenting vote, offer good faith solutions to help the state move forward toward a goal that all Texas patients and families facing serious illness have the information and opportunity to choose care that fits their individual circumstances and values, and care that is of the highest possible quality based upon excellent interdisciplinary education and training opportunities.

Recommendations

- 1.** Texas should adopt statutory language for supportive palliative care (SPC) as distinct from hospice palliative care (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.
- 2.** Texas policy should promote structured advance care planning (ACP) as a routine standard for medical care at all stages of life. Texans should be educated on the benefits of ACP and the options it provides. With informed consent, structured ACP discussions can come from any provider that sees a patient on a regular basis, whether it be a primary care provider, therapist, or specialist. Proxy decision makers for the patient should be included in these conversations whenever possible. Information from ACP conversations should be entered into written and signed advance directives and recorded in the medical records of each patient seen at least annually, no matter the purpose of a visit. The state should establish a digital repository to allow emergency responders, healthcare providers and institutions, and families/individuals easy and timely access to advance planning documents.
- 3.** Texas policy should encourage the creation of enough interdisciplinary training opportunities to assure sufficient workforce for hospice and palliative services. A plan to achieve this goal begins with a comprehensive review of current and future demand for palliative care. Resources are needed now for the entire optimal interdisciplinary palliative care team. Appropriations should support schools, academic health care facilities, and programs leading to education, training, and certification specialty preparation. Funding is needed both for discipline specific and interprofessional training of physicians, advanced practice registered nurses (APRNs), physician assistants (PAs), nurses, social workers, chaplains, and pharmacists, including the following:
 - a.** Graduate medical education dollars for hospice and palliative medicine (HPM) fellowships for physicians;
 - b.** Graduate education dollars for establishing and advancing hospice and palliative care fellowship programs for advanced practice providers (APRNs and PAs), social workers, psychologists, pharmacists, and chaplains;
 - c.** Support for interprofessional training across all disciplines and levels of education and practice; and
 - d.** Continuing education hours for specialty supportive palliative care and hospice care for professional license renewal.

Recommendations

- 4.** Texas Medicaid should use financial incentives and other strategies to promote the establishment of high quality interdisciplinary palliative care programs and services. The pathway for increasing SPC access through Medicaid value-based initiatives includes:
 - a.** Commissioning a comprehensive claims based study by an academic research team using a state-of-the-art analytics/return on investment model to quantify the expected benefits to Texas, including Medicaid cost savings, from expanding the availability of SPC services;
 - b.** Engaging Medicaid Managed Care Organizations (MCOs), hospitals, and other providers on the benefits of palliative care for reducing readmissions and other preventable hospital stays;
 - c.** Recognizing hospitals and community based programs that meet the high standards for Joint Commission or other similar palliative care certification, including by providing a modest financial reward; and
 - d.** Making advance planning a benefit of the state's Medicaid program and considering additional incentives to facilitate advance planning conversations, especially for new nursing home residents.
- 5.** Texas should expand analysis and public reporting on palliative care metrics within a state level dashboard. The dashboard could be published and updated regularly on the state's Palliative Care Information and Education Website.
- 6.** An effective state policy to address the multidimensional opioid crisis should involve thoughtful strategies that:
 - a.** Define the opioid epidemic as part of a larger context of substance abuse and addiction disorders;
 - b.** Continue and increase support for programs in both outpatient and inpatient settings that seek to prevent and manage addiction;
 - c.** Promote education for the public as well as health care professionals regarding non-opioid and non-pharmacologic methodologies for coping with chronic pain; and
 - d.** Offer a balanced, evidence based, and interdisciplinary approach to the regulation of opioid based medications, particularly acknowledging the needs of patients and providers involved in supportive palliative care, hospice palliative care, and oncology.

5. Introduction

Beginning with its first meeting in February 2016, the Palliative Care Interdisciplinary Advisory Council (“Council”) has pursued a mission to increase the availability of patient and family focused palliative care in Texas. As part of this charge, every two years, this multi-stakeholder committee reports consensus findings and recommendations to the Executive Commissioner of the HHS system and the Texas Legislature. In its first report, the Council addressed the frequent misunderstanding by health care professionals and the public alike that palliative care is synonymous with end of life care. Palliative care is not end of life care. It offers specialized, multidisciplinary support to relieve a patient’s symptoms, pain, and stress at any stage of a life threatening illness. While hospice palliative care (HPC) helps patients in the terminal stage of serious illness, supportive palliative care (SPC) is most effective when started early as part of an individual’s overall treatment plan. A growing body of evidence shows that SPC improves quality of life, reduces patient and caregiver burden, and lowers medical costs. In some cases, SPC may be combined with curative treatments that extend life or promote recovery from serious illness.

Since inception, the Council has worked with the state’s Palliative Care Information and Education program to catalyze a sustained quality improvement effort that aims to make Texas a national leader for providing appropriate, compassionate, and high quality palliative care to patients and families at any stage of serious illness. To date, significant activities and accomplishments from this endeavor include:

- Publishing an inaugural legislative report,¹ and now a second report, with recommendations and guidance for increasing the availability of patient and family focused palliative care in Texas;
- Launching the first Texas Health and Human Services (HHS) system palliative care website resource for patients, families, and professionals;²

¹ Texas Palliative Care Interdisciplinary Advisory Council (November 2016). *Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 85th Texas Legislature*. Retrieved from <https://hhs.texas.gov/sites/default/files/documents/laws-regulations/reports-presentations/2016/tx-palliative-care-interdisciplinary-advisory-council-recs-85th-leg-nov2016.pdf>

² See Texas Health and Human Services Webpage on Palliative Care <https://hhs.texas.gov/services/health/palliative-care>

- Developing and conducting annual palliative care continuing education events starting in 2017, awarding about 600 continuing education hours to date for interdisciplinary professionals;
- Establishing methods to track and report on key measures of palliative care access;
- Advancing a statewide, population based data collection initiative to assess completion of advance care planning documents in Texas;³ and
- Elevating the profile of serious illness care as a significant area of opportunity for raising overall healthcare quality in Texas.⁴

In its initial assessment, the Council concluded that the available evidence supported the Legislature’s belief, as described in HB 1874,⁵ that broad advances in access to palliative care are possible in Texas. In this updated review, the Council finds the state progressing in developing palliative care workforce and infrastructure, although much work remains ahead, particularly in designing relevant benefit and payment models, to meet the growing demand for SPC services.

Over the past two years, indicators of SPC access tracked by the Council have shown improvement. For example, for inpatient services, the Council previously reported that in 2014 only about 42% of Texas hospitals with 50 or more beds provided SPC.⁶ Texas performance significantly trailed the national rate of 67%, as calculated by the Center to Advance Palliative Care (CAPC), earning the state a “C” report card rating compared to the nation’s “B” rating overall.

CAPC publishes state level results only periodically, so the Council requested that HHSC staff provide routine monitoring using Texas specific data collected as part of the American Hospital Association (AHA) Annual Survey of Hospitals. The AHA survey, administered for Texas by the Department of State Health Services, is the primary-- though not the only-- source used by CAPC to compile its report card metric. Using only the AHA data, Texas staff largely corroborated the earlier CAPC

³ Texas Department of State Health Services (2018). *Texas Behavioral Risk Factor Surveillance System Questionnaire*. p. 38. Retrieved from <https://www.dshs.texas.gov/chs/brfss/attachments/2018-Texas-BRFSS-Survey.pdf>

⁴ See Texas Health and Human Services Healthcare Quality Plan on the Medicaid and CHIP Quality and Efficiency Improvement website: <https://hhs.texas.gov/about-hhs/process-improvement/medicaid-chip-quality-efficiency-improvement>

⁵ For more on House Bill 1874, 84th Texas Legislature, 2015 see Texas Legislature Online: <https://capitol.texas.gov/BillLookup/History.aspx?LegSess=84R&Bill=HB1874>

⁶ The National Palliative Care Report Card is available at www.capc.org and www.npcrc.org.

result for the state and have now followed emerging trends through 2016 (see Table 1). Over this time, 12 Texas hospitals added a palliative care program, and the state rate now stands just shy of 50%. Nevertheless, despite the gains, the Texas rate in 2016 still trails the 2013 national rate.

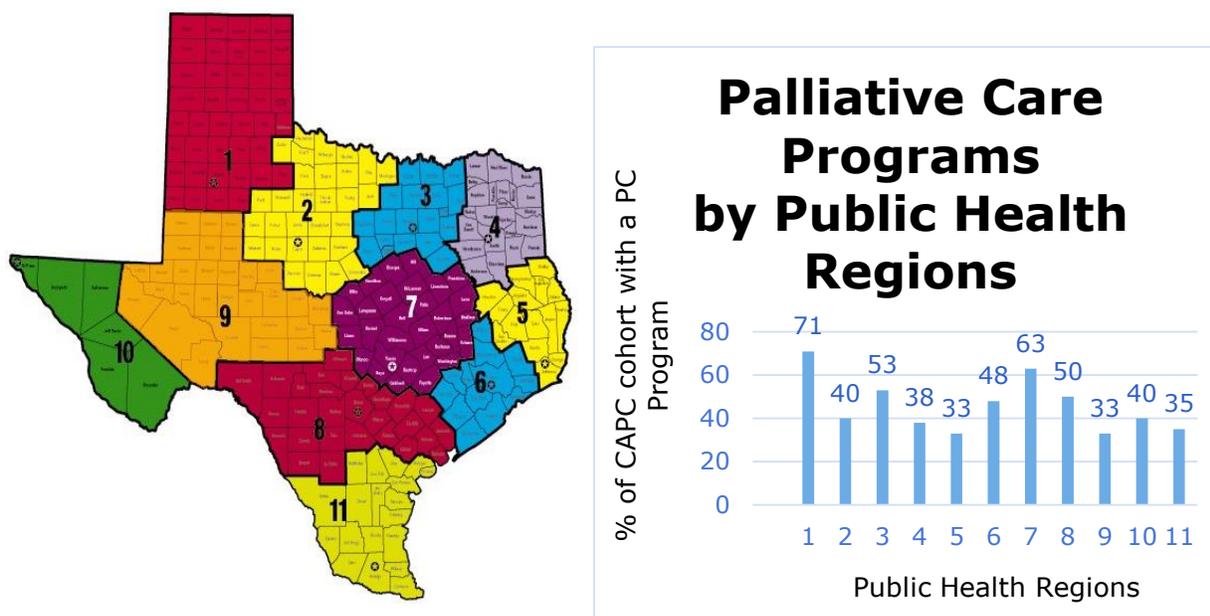
Table 1. Texas vs. CAPC Grade

Source	Data Year	Grade	Total Programs/ Hospitals (≥ 50 beds)	> 300 beds
CAPC National	2012/ 2013	67%	(1,591/2,393)	90% (659/732)
CAPC Texas	2012/ 2013	43%	(85/198)	66% (37/56)
In-house Texas	2014	42%	(86/205)	71% (42/59)
In-house Texas	2015	46%	(96/207)	71% (41/58)
In-house Texas	2016	49%	(98/201)	76% (44/58)

Note: Results are based on the CAPC defined hospital cohort.⁷

⁷ Analyses were limited to general medical and surgical, cancer, or heart hospitals with fifty or more licensed beds based on data from the American Hospital Association Annual Survey of Hospitals. Veterans Administration and Indian Health Service facilities were excluded. The CAPC method does not clearly distinguish hospital run palliative care programs from contracted services.

Figure 1. Texas Palliative Care (PC) Programs by Public Health Region (PHR), 2016



PHR	# Hospitals (50 or more beds)	# with PC Program ⁸	% with PC Program
1	7	5*	71%
2	5	2	40%
3	57	30***	53%
4	13	5	38%
5	9	3*	33%
6	40	19*	48%

PHR	# Hospitals (50 or more beds)	# with PC Program ⁵	% with PC Program
7	24	15*****	63%
8	18	9	50%
9	6	2	33%
10	5	2	40%
11	17	6*	35%
Total	201	98	49%

⁸ Note: PHRs denoted with one asterisk (*) gained one inpatient SP program between 2014 and 2016; PHR 3 denoted by (***) gained three programs, and PHR 7 by (*****) gained five programs. The number of programs in other regions remained the same.

HHSC staff also reviewed the AHA data to provide a more granular analysis of the availability of hospital palliative care programs in Texas, which revealed that access to inpatient palliative care services varies significantly from community to community. As shown above (Figure 1), a much lower percentage of hospitals in Public Health Region (PHR) 5 (East Texas), PHR 9 (West Texas), and PHR 11 (Rio Grande Valley) offer palliative care services than hospitals in other parts of the state. While most regions clearly trail the nation, PHR 1 (Panhandle) and PHR 7 (Austin/Central Texas) now have rates that are near or above the national average. Both regions added hospital programs over the past two years, including five new programs in PHR 7. Other regions adding at least one program include PHR 3 (Metroplex), gaining three programs, along with PHR 5, PHR 6 (Houston), and PHR 11, each gaining one.

As with hospitals, more interdisciplinary professionals are entering the field of palliative care (Table 2). Between 2015 and 2017, Texas physicians with a hospice and palliative medicine (HPM) specialty increased by 21%, including a 53% jump for doctors listing HPM as their primary specialty; certified Advanced Practice Registered Nurses increased by 59%; Certified Hospice Medical Directors by 37%; and palliative medicine fellows by 35%.

Table 2. Growth by Palliative Care Profession, Texas, 2015 - 2017

Professional Category	Number 2015	Number 2017	% Increase
Physicians with Palliative Specialty	275	332	21%
Primary	51	78	53%
Secondary	224	254	13%
Certified APRN	46	73	59%
Certified Hospice Medical Director	19	26	37%
Palliative Medicine Fellow	20	27	35%

Source: Health Professions Resource Center, Center for Health Statistics, DSHS

Table 3. Physicians with Primary or Secondary Specialty in Hospice and Palliative Medicine (HPM), by PHR, 2015 vs 2017

Public Health Region	# HPM Physicians 2015	# HPM Physicians 2017	# per 100,000 population (age 18 years and older), 2017	# per 100,000 population (age 65 years and older), 2017
1	9	12	1.8	9.7
2	7	8	1.8	7.9
3	62	77	1.3	9.0
4	12	16	1.7	7.4
5	10	15	2.4	11.0
6	74	89	1.7	11.7
7	41	46	1.8	11.1
8	36	39	1.8	9.5
9	11	9	2.0	10.4
10	3	4	0.6	3.6
11	10	17	1.0	5.8
Totals	275	332	1.6	9.5

Source: Health Professions Resource Center, Center for Health Statistics, DSHS

The increase in palliative care workforce appears broadly distributed across Texas (Table 3). Only one region, the highly rural PHR 9 (West Texas), experienced a decline in palliative care physicians. Two regions with significant needs, PHR 5 (East Texas) and PHR 11 (Rio Grande Valley), saw very positive growth in HPM specialists (50% or more) relative to their 2015 baseline.

Even with this initial progress, the Council recognizes that substantial gaps in care persist. Service levels and professional resources for palliative care remain below rates found in most other states, and, as leading experts point out, demand for

patient-centered and family-focused palliative care will only continue to grow.⁹ The state still faces notable challenges to expand the availability of palliative care services to the national average. Moreover, within Texas, some communities, such as the Rio Grande Valley, El Paso, and rural areas generally, appear particularly disadvantaged with regard to the availability of palliative care infrastructure.

Over the past two years, the Council heard from healthcare professionals, experts, and stakeholders and reviewed a wide array of research and literature to create the recommendations discussed in this report. During this deliberative process a number of key findings emerged. First and foremost, the Council found that the development and introduction into the market of innovative palliative care service models is hampered by the lack of a statutory definition to distinguish SPC from hospice. Second, honoring the wishes of patients and families should be the core value for palliative care practitioners. Third, across all disciplines, palliative care specialists remain in short supply relative to need, and additional resources for training and education are needed. Fourth, palliative care has already demonstrated success as a value-based model and should be further incentivized along those lines. Fifth, as palliative care expands, greater transparency on quality and performance is needed to empower better decision making by patients, families, communities, providers, and policy makers. Finally, the opioid epidemic should be met with thoughtful public policy that acknowledges the needs of patients and providers involved in supportive palliative care, hospice palliative care, and oncology.

The recommendations that follow, all adopted with no dissenting votes from the Council's interdisciplinary members, reflect these findings and offer good faith solutions to meet the goals established by the Texas Legislature in HB 1874. The Council looks forward to continuing its service to the state of Texas and to helping ensure that all Texas families facing serious illness have the information and opportunity to choose care that fits their individual circumstances and values, and care that is of the highest possible quality based upon excellent interdisciplinary education and training opportunities.

⁹ Lupu, D., Quigley, L., Mehfoud, N., and Salsberg, E.S. (April 2018). The Growing Demand for Hospice and Palliative Medicine Physicians: Will the Supply Keep Up?. *Journal of Pain and Symptom Management*. 55(4).

6. Recommendations

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 pain and other distressing symptoms, and not being a burden to their family. Achieving these outcomes will require increased awareness among both health care professionals and patients that 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.¹⁰ To help get these important specialty services to Texans when most needed, Texas law should be clear about palliative care's two distinct specialty services, 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.

¹⁰ Sinclair, S., and Meier, D. (2017). How States Can Expand Access to Palliative Care. *Health Affairs*. Retrieved from <http://healthaffairs.org/blog/2017/01/30/how-states-can-expand-access-to-palliative-care/>

Discussion

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

“Supportive Palliative Care (SPC) means patient and family-centered health care that optimizes quality of life for seriously ill patients (high-risk of mortality or life-limiting illness) and their families by:

1. Anticipating, preventing, and treating a patient’s “total pain” or total suffering;
2. Addressing the physical, intellectual, emotional, cultural, social, and spiritual needs of the patient;
3. Facilitating patient autonomy; and
4. Ensuring that the patient receives relevant information to support the informed consent decision making process.

SPC is provided without regard to patient age or terminal prognosis and does not require the patient to decline attempts at cure or other disease modifying therapy.

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.”

To fortify this statutory definition, industry and stakeholders should develop minimum expectations for SPC services. To this end, the Council believes the standards outlined below reflect current consensus for the optimal practice of specialty SPC. However, patient and family needs, along with the availability of resources, will vary across the state. Standards of care should include sufficient flexibility to fit the diverse circumstances of Texas communities. A review of current SPC literature reveals that SPC programs adhering to the highest standards for SPC specialty practice consistently produce a wealth of benefits for patients, families, and health care professionals along with clear and enduring positive economic impacts.¹¹

¹¹ Morrison, R.S., Penrod, J.D., et al (2008). *Arch Intern Med.* 168(16), 1783-1790.; Penrod, J.D., Deb, P., et al (2010). *J Palliat Med.* 13(8), 973-979; Morrison, R.S., Dietrich, J., et al (2011). *Health Affairs.*30(3), 454-63 McCarthy I, Philastre MR, Fine RL, et al. (2014) *Health Services Research.* 50(1), 217-236; May, P., Garrido, M.M., et al. (2015). *J Clin Oncol.* 33(25), 2745-2752.; Sweeney, L., Halpert, A., Waranoff, J. (2007). *Am J Manag Care.* 13(2), 84-92.

While the Council believes it would be premature to adopt such standards in statute (due to a number of moving variables), the Council supports the following criteria as the current best practices that specialty SPC teams and programs should strive to meet:

1. An optimal, comprehensive SPC healthcare team should include:
 - a. one (1) prescribing healthcare clinician (i.e., physician, APRN, PA);
 - b. one (1) APRN, if possible, and/or a registered nurse;
 - c. one (1) social worker;
 - d. one (1) chaplain; and
 - e. any other person(s)/professional(s) who can enhance the quality of life for both the SPC patient and his/her family. Examples include pharmacists, physical/speech/occupational therapists, child life specialists, nutritionists, music therapists, art therapists, psychologists, specially trained volunteers, and more.

While the professional team listed above is recommended, the Council recognizes that not all health care organizations will be able to meet these optimal standards.

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. 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.

The lack of a clear statutory definition for SPC to distinguish it from hospice (which is defined) 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 an absence 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, while, as a result of non-beneficial and/or non-desired medical care, 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 living, personal care homes, and long term acute care) document persistent delays in access and poor communication/coordination/continuity of care causing medical team angst, increased financial cost, and subpar outcomes. 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 objective for garnering public and health care professional awareness and decreasing confusion. Once confusion is minimized, greater funding and educational opportunities will emerge to foster research and pilot programs to benefit those in need of SPC.

Defining SPC is an emerging phenomenon states are pursuing 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 reach this initial milestone go on to provide creative and innovative 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 creating multi-stakeholder 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".¹² The clear and concise acknowledgement by NAM of meaningful, but different health care roles for SPC and HPC adds evidence in support of further policy reform to define SPC as distinct from HPC in formal legislation.

Without clarifying legislative and educational efforts, SPC will likely 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.¹³ 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 recommend early SPC for all metastatic cancer patients within eight weeks of diagnosis, a standard even the largest Texas SPC programs will be challenged to meet.

In California, an intensive outpatient palliative care pilot -- Partners in Palliative Care -- is paving 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.¹⁴ The program also received the highest marks for patient and family

¹² Institute of Medicine of the National Academies (2014). *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. p 2.

¹³ Parikh, R.B., et al. (2013). Early Specialty Palliative Care – Translating Data in Oncology into Practice. *The New England Journal of Medicine*. 369, 2347-2351.

¹⁴ Partnership Healthplan of California (2017). *Partners in Palliative Care Pilot*. Retrieved From http://www.partnershiphp.org/Providers/Quality/Documents/Strategic%20Initiatives%202017/PHC%20Palliative%20Care%20Program%20Summary_3_23_17.pdf

satisfaction, with up to 95% of participants reporting that they always received the best possible care from their palliative care team.¹⁵ The Council believes this type of data suggests the possibility of significant benefits not only to patients and families but also to both government (Medicaid) and non-government payers.

Policy Issue: Prioritize Advance Care Planning

Completion of advance care planning (ACP) documents, such as a living will,¹⁶ is the best way a person can ensure that his or her treatment wishes are honored during a period when he or she is incapacitated and unable to communicate and is paramount to helping palliative care services meet the individual and personal expressed needs of patients and families.

Recommendation

Texas policy should promote structured ACP as a routine standard for medical care at all stages of life. Texans should be educated on the benefits of ACP and the options it provides. With informed consent, structured ACP discussions can come from any provider that sees a patient on a regular basis, whether it be a primary care provider, therapist, or specialist. Proxy decision makers for the patient should be included in these conversations whenever possible. Information from ACP conversations should be entered into written and signed advance directives and recorded in the medical records of each patient seen at least annually, no matter the purpose of a visit. The state should establish a digital repository to allow emergency responders, healthcare providers and institutions, and families/individuals easy and timely access to advance planning documents.

Discussion

ACP is a process of regular discussion and documentation about patient goals and wishes for future medical care.¹⁷ Advance directives are the written, legal instructions produced by this process that record preferences for medical care and identify a proxy decision maker for a time when a person is unable to make decisions for him or herself. By planning ahead, a person can avoid unwanted or

¹⁵ Ibid.

¹⁶ A living will is known in Texas as a "Directive to Physicians and Family or Surrogates."

¹⁷ Emanuel, L.L., Gunten, C.F., and Ferris, F.D. (2000). Advance Care Planning. *Archives of Family Medicine*. 2000(9). Retrieved from https://micmrc.org/system/files/Advanced%20Care%20Planning_Archives%20of%20Family%20Medicine.pdf

unnecessary suffering and relieve caregivers and loved ones of decision-making burdens during moments of crisis or grief. More information on advance directives, including templates for statutory ACP documents, is available on the Texas Palliative Care Information and Education Website.¹⁸

A key concept for ACP is permission. As a general rule, palliative care and other professionals should avoid forcing a goals of care/advance directive discussion that a patient, family, or surrogate does not wish to have. No permission should mean no discussion.

With rare exceptions, goals of care and advance directive discussions should occur only when a patient is not ill or when his or her symptoms are under reasonable control. Professionals must not assume that goals of care discussions will necessarily lead to limitations on life sustaining treatments but instead may lead to aggressive treatments. Whether the patient prefers limited, intermediate, or the most intense treatments, his or her wishes should be clearly documented.

Evidence indicates that structured ACP approaches are most successful at fully eliciting these preferences. A structured process involves the use of validated tools to facilitate dialogue over a range of potential healthcare scenarios and alternatives. While this Council does not recommend a single approach for structured ACP, it does recognize that many evidence-based and reliable options exist.¹⁹

If a patient agrees to a goals of care and advance directives discussion, this Council has previously recommended a focus on living wills first, to be followed by creation of a medical power of attorney, if desired by the patient. Living wills generally allow a more accurate expression of patient preferences if terminally or irreversibly ill and unable to communicate. This is especially true of modern digital advance directives, including video recordings that allow persons more flexibility and ease for changing treatment preferences. Such directives are usable under Texas law since the Legislature approved digital signatures on advance directives. The most recent study to test whether the living will and medical power of attorney

¹⁸ See Texas Health and Human Services Palliative Care Webpage <https://hhs.texas.gov/services/health/palliative-care>

¹⁹ For a listing, see the Centers for Disease Control and Prevention (CDC) website: <https://www.cdc.gov/aging/advancecareplanning/index.htm> and CDC's Advance Care Planning -- Selected Resources for the Public: <https://www.cdc.gov/aging/pdf/acp-resources-public.pdf> (accessed September 18, 2018). ACP tools listed by the CDC include: Caring Conversations Workbook, Five Wishes, Consumer's Tool Kit for Health Care Advance Planning, and many others.

reduce non-beneficial treatments for seriously ill patients found stronger statistical effects for the living will.²⁰

Policy Issue: Address Palliative Care Provider Shortages

The need for palliative care is growing rapidly as the population ages, concurrent²¹ palliative care becomes more common, and healthcare reimbursement models increasingly favor value over volume. The best available estimates indicate that palliative care providers already are in short supply across the U.S., and that current training capacity is insufficient to keep up with population growth and the demand for services.²² Moreover, despite some recent gains, Texas noticeably trails the nation in the number of medical professionals per population with specialized hospice and palliative medicine (HPM) credentials. Given the significant time entailed to train new professionals, state policy makers must act now to plan for and meet future palliative care workforce requirements.

Recommendation

Texas policy should encourage the creation of enough interdisciplinary training opportunities to assure sufficient workforce for hospice and palliative services. A plan to achieve this goal begins with a comprehensive review of current and future demand for palliative care. Resources are needed now for the entire optimal interdisciplinary palliative care team.²³ Appropriations should support schools, academic health care facilities, and programs leading to education, training, and certification specialty preparation. Funding is needed both for discipline specific and interprofessional training of physicians, APRNs, PAs, nurses, social workers, chaplains, and pharmacists, including the following:

- a.** Graduate medical education dollars for HPM fellowships for physicians;

²⁰ Amol, K., Wright, A.A., Nicholas, L.H. (2015). Trends in Advance Care Planning in Patients with Cancer. *JAMA Oncology*. Retrieved from <https://jamanetwork.com/journals/jamaoncology/article-abstract/2383145>

²¹ Concurrent palliative care is when palliative care is delivered along with or concurrent to treatments seeking to cure or modify a disease.

²² Ibid (Lupu 2018).

²³ As previously mentioned, the council believes an optimal comprehensive SPC healthcare team should include one prescribing healthcare clinician (i.e. a physician, APRN, PA), one APRN, if possible, and/or a registered nurse, one social worker, one chaplain, and any other person(s)/professional(s) who can enhance the quality of life for the patient and their family, such as a pharmacist, physical/speech/occupational therapist, child life specialist, nutritionist, music therapist, art therapist, psychologist, specially trained volunteer, and more.

- b.** Graduate education dollars for establishing and advancing hospice and palliative care fellowship programs for advanced practice providers (APRNs and PAs), social workers, psychologists, pharmacists, and chaplains;
- c.** Support for interprofessional training across all disciplines and levels of education and practice; and
- d.** Continuing education hours for specialty supportive palliative care and hospice care for professional license renewal.

Discussion

According to the National Academy of Medicine, demand for palliative care far exceeds the supply of professionals trained to provide these services.²⁴ This shortage delays access to palliative care services. Delayed access can lead to unnecessary suffering along with preventable emergency department (ED) visits and hospitalizations -- all of which can be distressing for patients and families coping with serious and life-limiting illnesses. In its review of available evidence, this Council has found that despite recent improvements, palliative care workforce and infrastructure remain low throughout the state relative to need, and that some communities face particularly large disparities, including in the border region and rural areas generally.

House Resolution (HR) 1676, which passed the U.S. House of Representatives in 2018 and is currently pending in the Senate, provides a potential opportunity for increasing interdisciplinary palliative care education using a train the trainer model.²⁵ The resolution, known as the Palliative Care and Hospice Education and Training Act, directs the Department of Health and Human Services to award grants for the purpose of increasing professional development opportunities for palliative care medical school faculty, nurse educators, and other interdisciplinary trainers. The resolution would accomplish this goal, in part, through the creation of a national network of Palliative Care and Hospice Education Centers that support interdisciplinary palliative care faculty/trainers. Should HR 1676 become law, Texas will be well positioned to become a location for an education center. If the resolution does not pass, many of the concepts it incorporates are worth studying to implement with state public and private sector resources.

²⁴ Ibid Institute of Medicine of the National Academies (2014).

²⁵ Palliative Care and Hospice Education and Training Act, H.R. 1676, 115th Congress. (2017). Retrieved from <https://www.congress.gov/bill/115th-congress/house-bill/1676>

Policy Issue: Expand SPC Programs as a Value-Based Model

Effective supportive palliative care (SPC) requires an interdisciplinary team approach. Such teams are labor intensive and reimbursement poor. Unlike hospice, SPC teams, whether functioning in the hospital, nursing home, office, or home setting do not receive per diem payments, yet they save payers, including Medicaid, money.²⁶ Unfortunately, for Medicaid and other payers, about 50% of Texas hospitals lack SPC programs. Likewise, only a small number of office and community-based SPC programs have been identified in Texas. As a major purchaser of health-care, particularly for individuals with serious illnesses, the state itself can reform program and benefit designs to drive system-wide changes leading to earlier access to palliative care services, better outcomes and experience for patients and families, and lower healthcare costs for all Texans.

Recommendation

Texas Medicaid should use financial incentives and other strategies to promote the establishment of high quality interdisciplinary palliative care programs and services. The pathway for increasing SPC access through Medicaid value-based initiatives includes:

- a.** Commissioning a comprehensive claims based study by an academic research team using a state-of-the-art analytic/return on investment model to quantify the expected benefits to Texas, including Medicaid cost savings, from expanding the availability of SPC services;
- b.** Engaging Medicaid Managed Care Organizations (MCOs), hospitals, and other providers on the benefits of palliative care for reducing readmissions and other preventable hospital stays;
- c.** Recognizing hospitals and community based programs that meet the high standards for Joint Commission or other similar palliative care certification, including by providing a modest financial reward;
- d.** Making advance planning a benefit of the state's Medicaid program and considering additional incentives to facilitate advance planning conversations, especially for new nursing home residents.

²⁶ Ibid. Morrison, R.S., Dietrich, J., et al., 2011

Discussion

Palliative care stands out as a successful model for value-based healthcare. With timely SPC services, numerous studies convincingly demonstrate that:

- Patients endure less pain and other suffering,² have fewer hospital readmissions,²⁷ survive longer for diagnoses of metastatic cancer,²⁸ receive fewer non-beneficial interventions,²⁹ have shorter intensive care unit (ICU) lengths of stay,³⁰ receive treatments more congruent with their wishes,³¹ and have higher patient satisfaction.^{32,33}
- Families experience reduced surrogate decision maker conflict and emotional distress with advance care planning,³⁴ improved family (and patient) satisfaction, less depression, better bereavement, and less post-traumatic stress symptoms when a seriously ill family member dies;³⁵ and

²⁷ Lorenz, K., Lynn, J., et al. (2008). *Ann Intern Med.* 148, 147-159; Wagner-Johnson, N., Carson, K., and Grossman, S. (2010). *Journal of Pain and Symptom Management.* 39(2), 180-185; Purcell, W.T., Grossman, S.A., et al. (2003). Abstract No. 2963. *Proc AM Soc Clin Oncol.* 22.; Riolfi, M., Buja, A., et al. (2014). *Palliative Med.* 28(5), 403-411

²⁸ Temel, J.S., Greer, J.A., et al (2010). *The New England Journal of Medicine.* 363, 733-742; Bakitas, M., Tosteson, T., et al. (2014). *Journal of Clinical Oncology.* 32(5)s, abstract 9512; Lilly, C.M., De Meo, D.L., et al. (2000). *The American Journal of Medicine.* 109(6), 469-475.

²⁹ Purcell, W.T., Grossman, S.A., et al (2003). Abstract No. 2963. *Proc Am Soc Clin Oncol.* 22

³⁰ Norton, S.A., Hogan, L.A., et al. (2007). *Critical Care Medicine.* 35(6), 1530-1535; Campbell, M.L., Guzman, J.A.(2003). *Chest.* 123(1). 26-71

³¹ Lautrette, A., Darmon, M., et al. (2007). A communication strategy and brochure for relatives of patients dying in the ICU. *The New England Journal of Medicine.* 356(5), 469-478

³² Parker, S.M., Remington, R., et al. (2013). Patient outcomes and satisfaction with care following palliative care consultation. *Journal of Hospice and Palliative Nursing.* 15(4), 225-232

³³ Chand, P., Gabriel, T., et al. (2013). Inpatient palliative care consultation: describing patient satisfaction. *The Permanente Journal.* 17(1), 53-55

³⁴ Chiarcharo, J., Praepannaral, B., et al. (2015), *Annals ATS.* 12(10), 1528-1532; Allen, R.S., Allen, J.Y., et al. (2008). *Journal of the American Geriatrics Society.* 56(10), 1904-1909

³⁵ Cassarett, D., Packard, A., et al. (2008). *Journal of the American Geriatric Society.* 56, 593-599;; Dionne-Odom, J.N., Andres, A., et al (2014). Abstract LBA9513. *Journal of Clinical Oncology.* 32(5)s; Heyland, D.K., Allan D.E., et al. (2009). *Open Medicine.* 3(2), 101-110

- Payers, whether commercial, governmental, or private, see significantly lower costs – especially with early SPC consultation.^{36,37,38}

In other words, evidence-based SPC delivered by skilled interdisciplinary professionals early in the course of serious illness clearly meets the Triple Aim standard for care that achieves better outcomes and higher patient satisfaction at lower total cost.

As with other medical treatments, decisions to provide SPC services should be determined by the needs and wishes of patients and their families. However, cost avoidance associated with SPC also appears substantial, particularly for the nation’s major public payers, Medicare and Medicaid. Together, Medicare and Medicaid account for a sizeable portion of serious illness care in the United States and thus are well positioned to lead industry wide efforts to improve outcomes for these patients and their families, as well as to lower costs.³⁹

In the most recent well-designed study on SPC services in Medicaid, hospital palliative care teams were shown to cut costs for seriously ill Medicaid inpatients in New York by \$4,000 - \$7,500 per discharge, compared to a matched set of patients receiving usual care.⁴⁰ Palliative care patients spent less time in intensive care, were less likely to die in intensive care, and were more likely to receive hospice referrals. The authors projected overall savings from expanding access to palliative care teams at between \$84 million and \$252 million for the New York

³⁶ Morrison, R.S., Penrod, J.D., et al (2008). *Arch Intern Med.* 168(16), 1783-1790; Penrod, J.D., Deb, P., et al. (2010). *Journal of Palliative Medicine.* 13(8), 973-979; Morrison, R.S., Dietrich, J., et al. *Health Affairs.* 30(3), 454-463; McCarthy, I.M., Philastre, M.R., Fine, R.L., et al. (2014). *Health Services Research.* 50(1), 217-236; May, P., Garrido, M.M. Cassell, J.B., et al. (2015). *Journal of Clinical Oncology.* 33(25), 2745-2752; Sweeney, L., Halpert, A., et al. (2007). *The American Journal of Managed Care.* 13(2), 84-92

³⁷ McCarthy, I., Philastre, M.R., Fine, R.L. (2014). Cost Savings from Palliative Care Teams and Guidance for a Financially Viable Palliative Care Program. *Health Services Research.* Retrieved from <https://onlinelibrary.wiley.com/doi/abs/10.1111/1475-6773.12203>

³⁸ May, P., Normand, C., Cassel, J.B., Del Fabbro, E., Fine, R.L., et al. (2018). Economics of Palliative Care for Hospitalized Adults with Serious Illness: a Meta-Analysis. *JAMA Intern Med.* Retrieved from <https://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2678833>

³⁹ The National Academies of Medicine (2018). *Financing and Payment Strategies to Support High-Quality Care for People with Serious Illness: Proceedings of a Workshop.* Retrieved from <https://www.nap.edu/read/25071/chapter/1>

⁴⁰ Ibid (Morrison 2011).

Medicaid program, without accounting for additional cost avoidance from reductions in future hospitalizations.⁴¹ The Council believes Texas should examine its own claims data to estimate return on investment from SPC and follow-up by introducing targeted Medicaid initiatives and incentives to accelerate the spread of this value-based model across the state.

As a large purchaser of healthcare, the state has many opportunities to drive value through benefit designs, educational efforts, and incentives. Texas Medicaid puts a portion of both MCO and hospital reimbursement at risk based on performance. These performance incentives are strongly influenced by rates of potentially preventable events, including avoidable admissions, readmissions, and emergency department visits. Analytic and educational efforts to quantify and report benefits to MCOs and hospitals from reductions in potentially preventable events for seriously ill patients, and the role of SPC in achieving these reductions, even within the current Medicaid payment model, would help encourage formation of new SPC teams.

To further ensure that spending on serious illness care aligns with evidence-based healthcare and value, Texas Medicaid should incorporate additional incentives into Medicaid. To start, Medicaid could provide a small payment adjustment to hospitals that achieve advanced certification for palliative care from The Joint Commission. This certification recognizes hospital inpatient programs that demonstrate exceptional patient and family-centered care. Eligible organizations must maintain a full-time service led by an interdisciplinary team, adhere to guidelines grounded in evidence and expert consensus, practice effective care coordination and communication among all providers in the hospital setting, and have the ability to provide palliative care to its entire inpatient population. Ongoing data collection, performance measurement, and quality improvement are fundamental to the certification process. Similar incentives for high performing community based palliative care programs should also be implemented.

Strengthening Medicaid's role with ACP offers another avenue to pursue value-based care. Texas Medicaid should adopt an ACP benefit in medical policy, as Medicare and California Medicaid have already done and other state Medicaid programs are considering. Structured advance planning promotes earlier access to SPC, less unwanted care and suffering, and lower total healthcare spending. Paying doctors, advance practice providers, nurses, and social workers for ACP

⁴¹ Accounting for medical inflation since the ending time period for the study data (2007), the estimate for cost avoidance in 2017 dollars would be \$113 million to \$341 million.

consultations would result in some additional program spending upfront, but these relatively minor outlays would be more than offset by reductions in avoidable emergency department and hospitalization costs.⁴²

An initial pilot covering new nursing home residents offers a promising option to leverage ACP for an early, meaningful success. Medicaid covers more than 60% of individuals in Texas nursing homes.⁴³ These individuals account for over \$3 billion in nursing home costs alone, with additional spending for hospital, professional, and other acute care services.⁴⁴ Based on evidence from a randomized controlled trial, when nursing home patients engage in ACP, they use hospital services less frequently and have 33% lower global costs of care.⁴⁵ Patient and family satisfaction scores also are higher with no change in patient mortality. This increase in patient and family satisfaction combined with lower costs of care epitomizes the best hopes for transforming Medicaid from a volume to a value-based system.

Policy Issue: Establish a Statewide Palliative Care Dashboard

As SPC service availability expands across Texas, state policy must drive the industry to meet the highest standards for quality and efficiency. Public reporting, in conjunction with an effective business intelligence and informatics strategy, is essential for achieving accountability in healthcare and empowering patients, families, communities, providers, and policy makers to make informed choices. Currently, Texas does not support a stakeholder facing dashboard that shows metrics specifically for palliative care.

⁴² The Council's recommendation would make Current Procedural Terminology (CPT) codes 99497 and 99498 payable under Texas Medicaid policy. Currently, the state only covers Medicare cost sharing amounts for clients dually eligible for Medicaid and Medicare.

⁴³ Henry J. Kaiser Family Foundation (2017). *Medicaid's Role in Nursing Home Care*. Retrieved from <https://www.kff.org/infographic/medicaids-role-in-nursing-home-care/>

⁴⁴ As reported by HHSC for state fiscal year 2017.

⁴⁵ Molloy, D.W., et al. (2000). Systematic Implementation of an Advance Directive Program in Nursing Homes: A Randomized Trial. *JAMA*. 283(11), 1437-1444. Retrieved from <https://jamanetwork.com/journals/jama/fullarticle/192502#full-text-tab>

Recommendation

Texas should expand analysis and public reporting on palliative care metrics within a state level dashboard. The dashboard could be published and updated regularly on the state's Palliative Care Information and Education Website.

Discussion

High quality data informatics are essential to implement effective value-based and quality improvement initiatives and to support decision making for patients, providers, payers, and policy makers. However, currently, very little actionable information is available related to palliative care, particularly SPC, even though the field has emerged as a significant area of opportunity for producing value (better outcomes and patient experience at lower cost) in healthcare. As routine data collection, measurement, and reporting are hallmarks of a learning healthcare system, the state and the Palliative Care Information and Education Program must focus more resources to support business intelligence initiatives, including dashboards, that deliver relevant information quickly and efficiently to SPC stakeholders.

Initially, an SPC dashboard could be built from data already collected in Texas. These sources include Medicaid and Medicare claims, workforce and licensing information, and surveys of hospitals, providers, and individuals. Some statistics calculated from this existing data are included in this report. However, a deeper dive into this data offers rich possibilities to identify variations in access, services, and outcomes related to palliative care; monitor fidelity to key processes and standards; and estimate return on investment for SPC interventions. Over time, the dashboard should evolve to include metrics that become available through electronic records systems, expanded population surveillance, or other means.⁴⁶

The dashboard should highlight the most meaningful measures for assessing access to high quality, patient and family centered SPC services at the earliest appropriate time in the course of a serious illness. While the Council does not suggest beginning with public reporting at a provider level, the dashboard should include breakouts for geographic areas that represent markets for services. As

⁴⁶ For example, the state's first population level data on advance care planning is currently being collected through the Behavioral Risk Factor Surveillance System (BRFSS) and will be available to include on a dashboard in 2019. The BRFSS, established in 1984, is the nation's premier survey for collecting data from U.S. residents in every state regarding their health related risk behaviors, chronic health conditions, and use of preventive services. The system is administered, predominantly, at a state level and operates through a state-federal cooperative agreement.

Texas is a large, diverse state, reporting by geography and other important demographics could assist policy makers to identify and address disparities across Texas communities.

The development of this new capability should be led by interdisciplinary SPC practitioners but will require input and collaboration by experts across many other fields, including health services research, performance measurement, implementation science, and information technology. The voice of patients and families must always be heard as well. To achieve maximum effectiveness, resources should be dedicated to commission academic or other professionals to compile data, perform the needed analytics, and create meaningful displays and visualizations. The state's Palliative Care Information and Education Website provides an established option as a location to publicly report and routinely update a state palliative care dashboard.

Policy Issue: Seek a Balanced Response to the Opioid Crisis

Opioid related overdose deaths have indeed increased in recent years both across the nation and here in Texas. The trend across the nation is to react swiftly with new regulations and restrictions on the use of and prescribing of opioid medications. These efforts may be aimed at prescribers, pharmacists, and even patients.

However, measuring deaths from overdose does not tell the complete story behind the unfortunate misuse and abuse of opioids. Furthermore, it does not speak to the thousands of patients who experience improvements in quality of life with proper use of these medications.

Recommendation

An effective state policy to address the multidimensional opioid crisis should involve thoughtful strategies that:

- a.** Define the opioid epidemic as part of a larger context of substance abuse and addiction disorders;
- b.** Continue and increase support for programs in both outpatient and inpatient settings that seek to prevent and manage addiction;
- c.** Promote education for the public as well as health care professionals regarding non-opioid and non-pharmacologic methodologies for coping with chronic pain; and

- d. Offer a balanced, evidence based, and interdisciplinary approach to the regulation of opioid based medications, particularly acknowledging the needs of patients and providers involved in supportive palliative care, hospice palliative care, and oncology.

The goal of the Council’s recommendation is to encourage deeper exploration regarding opioid abuse, highlight educational opportunities, reduce unintended consequences of policy changes, and facilitate a truly meaningful response to this growing epidemic.

Discussion

Misuse of opioid medications is indicative of the broader issues of substance abuse and addiction disorders. Whether a person is taking their neighbor’s pain pills, binge drinking, or snorting cocaine, the reason for initial use is often far more telling than the particular mechanism. Often individuals lack positive coping mechanisms to combat either the everyday stresses of life or extreme circumstances such as physical, sexual, or emotional abuse as well as trauma. Without alternatives, a person may turn to negative coping mechanisms, which include substance misuse and abuse. Indeed, there are many links between poor coping skills and increased likelihood of addiction. While treatment and recovery programs are vital to decreasing dependence on chemical coping, the Council recommends continued efforts toward preventing substance abuse through public education and funding for counseling services. These should be available in the community setting as well as in the acute setting (i.e. hospital).

Pain is real. It effects everyone at some point in their lives—often serving as a warning of some greater problem. Unfortunately for some people, the pain continues beyond the initial injury and perhaps even long after the injury has healed. It has been estimated that at least 100 million Americans are affected by chronic pain at the cost of roughly \$600 billion dollars a year in combined healthcare expenses and lost productivity.⁴⁷ Yet, while Americans consume more opioid based medications as compared to any other country, the word “pain” continues to be present in five of the top ten chief complaints in the ED. Clearly, opioids have been unable to completely address patients’ pain despite decades of increasing efforts.

⁴⁷ Committee on Advancing Pain Research, Care, and Education (2011). *Relieving Pain in America: A Blueprint for Transforming Prevention, Care, Education, and Research*. *Institute of Medicine of the National Academies*. Retrieved from <https://www.nap.edu/read/13172/chapter/1>

In the middle of the 20th century, Dame Cicely Saunders introduced the concept of total pain. This model broadened the definition of pain to include not just the physical but the emotional, spiritual, and social elements of a person's being. The level of suffering experienced in each aspect of a person's life contributes to the overall level of pain that person is living with. In addition, increased distress in one category can manifest itself in another. For years, researchers have established correlations between emotional and physical ailments. Countless studies link depression with physical pain. This includes patients that may have presented with a physical complaint but actually suffered from depression and patients with chronic pain who subsequently developed depressive symptoms.⁴⁸ There is a significant association between sexual abuse and chronic pelvic pain.⁴⁹ Similarly, social factors affect a patient's pain. Compared to the most affluent in society, moderate and low income populations are one and a half time more likely to have chronic pain.⁵⁰ Pain and suffering are more complex than would appear on the surface.

While this notion has influenced recent clinical guidelines for the management of chronic pain, palliative care (including SPC and HPC) has long recognized the validity of total pain and has always incorporated this concept into the practice of helping patients and families navigate the effects of serious illness. The principle of matching a treatment to the root cause of suffering is a sacred tenet of palliative care. It allows for better validation of a patient's suffering while preventing the tunnel vision that can occur in developing treatment regimens. Opioids have their role in the treatment of physical pain but so do non-opioid based treatments such as NSAIDs, neuroleptics, or even personally tailored transdermal medications. Furthermore, treating emotional or spiritual suffering with opioids is inherently unsuccessful. Health care providers know this; however, until recently the medical community, pharmaceutical companies, and the general public have had both a limited definition of pain (ex. Pain is the 5th vital sign from the 1990s) and limited resources to adequately address the root cause of suffering. As such, opioids have largely become the mainstay for both the treatment of generalized pain and for

⁴⁸ Trivedi, M.H. (2004). The Link Between Depression and Physical Symptoms. *The Primary Care Companion to the Journal of Clinical Psychiatry*. 6(1), 12-16. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC486942/>

⁴⁹ Lampe, A., Solder, E., et al. (2000). Chronic Pelvic Pain and Previous Sexual Abuse. *Obstetrics and Gynecology*. 96(6), 929-933. Retrieved from <http://europepmc.org/abstract/med/11084180>

⁵⁰ Davies, K.A., Silman, A.J., et al. (2009). The association between neighborhood socio-economic status and the onset of chronic widespread pain: results from the EPIFUND study. *13(6)*, 635-640. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2701988/>

copied with chronic pain. Broadening the definition of pain allows for broadening the definition of an analgesic. It opens the door to countless positive coping mechanisms meant to address all aspects of suffering that contribute to the patient's total pain. These could include counseling, exercise, faith groups, and music therapy. The Council recommends investing in education for the public as well as for health care professionals regarding non-opioid and non-pharmacologic methodologies for coping with and managing chronic pain.

Although it has been discussed that opioids may not completely resolve the larger concept of total pain, it is equally important to remember that opioid based medications remain some of the most effective tools for symptom relief. When utilized correctly, opioids are an essential part of an effective treatment plan for acute physical pain, chronic malignant pain, and dyspnea. This is especially true in patients suffering from severe or life ending illnesses—that is patients receiving palliative care or hospice services. Current responses to the opioid crisis may unintentionally marginalize this patient population. Limits on manufacturing create supply shortages and new policies complicate dispensing at local pharmacies. In general many prescribers have developed a misplaced fear of a medication that can actually bring tremendous relief from the symptom burden of advanced disease. Placing additional, unfounded restrictions and harsh penalties for prescribers would only deepen this fear. Already, there are deleterious effects on patients. Recent studies have shown that up to 42% of cancer patients have inadequate pain control and some patients must wait days while battling with unfounded insurance restrictions on opioid coverage.

With respect to patient care, under treating is just as egregious as overprescribing. To this effect, the Council cautions law makers against demonizing the medication itself and recommends a balanced approach to the regulation of opioid medications.

The opioid epidemic is a growing concern across the nation and the state. However, it should be noted that despite a roughly 22% decrease in the number of opioid prescriptions written over the last four years, the number of opioid overdoses has increased by 50%.⁵¹ During this same time frame, opinions have become polarized with opioid medications largely seen (by both public and provider) as either all good or all bad. While the Council agrees with the level of alarm, it is the opinion of the Council that the issue is more complex and

⁵¹ Doolittle, D. (2018). Following National Trend, Texas' Opioid Prescriptions Drop. *Texas Medical Association*. Retrieved from <https://www.texmed.org/Template.aspx?id=47453>

multilayered. As such, any mindful approach toward a meaningful solution would serve to be multilayered as well.

7. Conclusion

The 84th Texas Legislature (2015) established the Palliative Care Interdisciplinary Advisory Council to provide objective evaluation and consensus recommendations to increase the availability of patient and family-focused palliative care in Texas and to assist the HHS system with the establishment and operation of a palliative care information and education program. Since launching this ongoing initiative, the state has made discernable progress toward increasing awareness of palliative care and developing capabilities to deliver services across the state. To build on this momentum, the Council convened three times during 2018 in Austin to update the initial findings and recommendations it published in November 2016. The meetings occurred in full public view and in partnership with the many stakeholders committed to improving palliative care services in Texas. The Council's revised assessment reaffirms the Legislature's original belief that significant and broad improvements in palliative care are possible in Texas and such improvements will contribute to better outcomes, higher satisfaction, and smarter spending for patients, families, and payers. The Council hopes its second report can serve as a renewed catalyst for a sustained quality improvement effort and looks forward to continuing its work to make Texas the national leader for providing appropriate, compassionate, and high quality palliative care to patients and families at any age and at any stage of serious illness.

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List of Acronyms

Acronym	Full Name
ACS	American Care Society
ACP	Advance Care Planning
AHA	American Hospital Association
APRN	Advanced Practice Registered Nurse
ARU	Acute Rehabilitation Unit
ASCO	American Society of Clinical Oncology
CAPC	Center to Advance Palliative Care
CDC	Centers for Disease Control
CPR	Cardiopulmonary Resuscitation
CPT	Current Procedural Terminology
DNR	Do Not Resuscitate
ED	Emergency Department
EMS	Emergency Medical Service
ESAS	Edmonton Symptom Assessment Scale
HC	Hospice Care
HHSC	Health and Human Service Commission
HPC	Hospice Palliative Care
HPM	Hospice Palliative Medicine
HR	House Resolution
ICU	Intensive Care Unit
IOM	Institute of Medicine

Acronym	Full Name
LTCF	Long Term Care Facility
LTAC	Long Term Acute Care
MCO	Managed Care Organization
NAM	National Academy of Medicine
NEJM	New England Journal of Medicine
NSAID	Nonsteroidal Anti-Inflammatory Drugs
OOHDNR	Out of Hospital Do-Not Resuscitate
PA	Physician Assistant
PC	Palliative Care
PCIAC	Palliative Care Interdisciplinary Advisory Council
PHR	Public Health Region
PPS	Palliative Performance Scale
SPC	Supportive Palliative Care
TPIAC	Texas Palliative Interdisciplinary Advisory Council

Appendix

Texas Palliative Care Interdisciplinary Advisory Council (PCIAC) Personal Statement

As an appointed member of the Palliative Care Interdisciplinary Advisory Council, I have worked with my colleagues on the Advisory Council to improve palliative care and identify some of the barriers to increasing access, education, and awareness of supportive palliative health care services for the citizens of Texas. The attached report is the result of the Council's efforts.

The recurrent phenomena noted in research on supportive palliative care and in professional discussions are the lack of education and poor understanding of the difference between supportive palliative care and hospice care.

Based on research for this report and the professional experience of the members of the Advisory Council, the evidence is clear. Unless Texas provides a standalone definition of supportive palliative care that clearly delineates it from hospice, the fragmentation of care from clinicians and high symptom burden (unnecessary emotional, physical, spiritual and financial stressors) among consumers will remain.

Supportive palliative care has a proven record of success in enhancing quality of life for the consumer and relieving the burden on the clinician, while improving the fiscal medical resources.

Texas has a unique opportunity to improve the quality of life for some of the most vulnerable patients cared for across the lifespan. Texas has a proven supportive palliative care blueprint of care that can realistically meet the needs of consumers and clinicians while improving fiscal burden. The palliative care blueprint is based on recognition of a standalone supportive palliative care service line for all Texans.

The first step in achieving success is implementing a clear, legislative definition of supportive palliative care. The Advisory Council and palliative care experts reached consensus on the proposed definition to define and differentiate palliative care from hospice care. Defining supportive palliative care in a standalone chapter in the Texas Health and Safety Code will also create a clear service line delineation for care across practice settings.

Second, setting into motion a pilot study of supportive palliative care incorporating the quality and standards outlined in the report will provide a foundation for Texas to evaluate the need for future appropriations. While the supportive palliative care quality and standards outlined in the report may be aspirational for Texas in 2018, these accepted standards of practice help ensure standardization, quality, and safety to support positive patient outcomes across

Texas. "It should not matter the zip code you live in to determine the healthcare one receives."

It is my sincere hope that the members of the Legislature will recognize in the 2018 PCIAC report the progress Texas has made in regards to advancing supportive palliative care across the state. The PCIAC team's efforts with stakeholders at the local, state and national level have aided our endeavors to help more Texans who need supportive palliative care and those who care for them.

I am honored to work diligently among colleagues on this council. I am so appreciative of the council and legislature's time and consideration to help better the global quality of life for what Texans need and deserve during the most vulnerable and sacred time in their lives.

Warmest Regards,
Erin

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*"You treat a disease, you win, you lose. **You treat a person, I guarantee you, you'll win, no matter what the outcome**".*

- Patch Adams