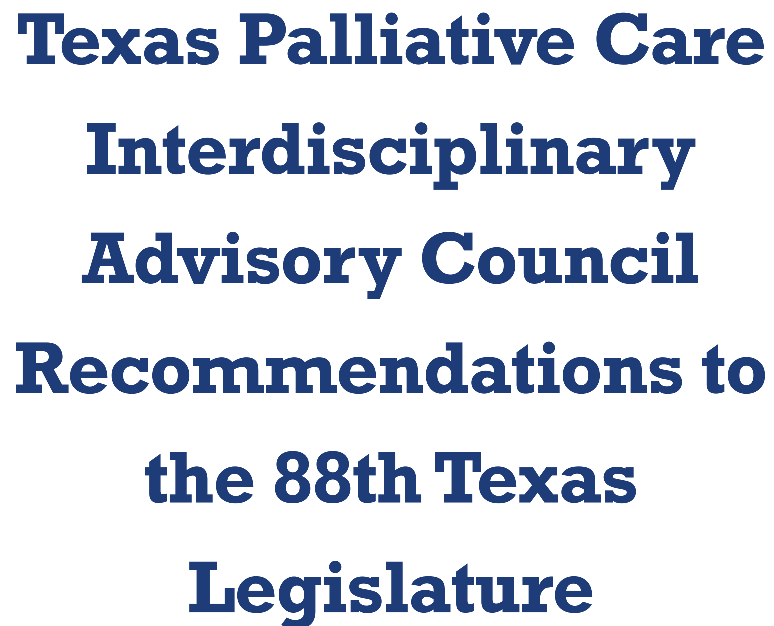

Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 88th Texas Legislature

As Required by

H.B. 1874, 84th Legislature, Regular Session, 2015

Health and Human Services Commission

October 2022

TEXAS
Health and Human Services

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.

Report Date
October 2022

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1. Letter from Chair

To: Governor Abbot, Members of the Legislature, and the HHS Commissioner:

Palliative Care is patient-centered, family-focused care that provides a patient with relief from the physical, emotional and spiritual symptom burdens caused from serious and often life limiting illness; is provided by a specialty interdisciplinary team offering an additional layer of support to the patient and family; and is appropriate for a patient of any age and at any stage of a serious illness, including day one of diagnosis. **Supportive Palliative Care** is best provided earlier in the course of serious illness as part of a collaborative and concurrent care team which includes efforts in disease modification, curative or noncurative therapy which can help a patient improve their quality of life and that of their care team during the course of serious illness more efficient and holistically while also improving health care fiscal stewardship. Similarly, **Hospice Palliative Care** aides the patient facing a terminal illness, at the end of life (six months or less prognosis) to ease the suffering and burden caused from the disease processes while assisting the patient and caregiver team with balancing comfort and function, refocusing their health care to the patient centered goals of care on what matters most to the patient. End of life care is provided while holistically and collaboratively alleviating end of life physical, emotional and spiritual symptom burdens, with the utmost focus on comfort care for the patient and greatest resource support for the family/caregiver team during the most difficult time in a patient's life.

The 2015 84th Texas Legislature, HB 1874 (Zerwas), established the Health and Human Services Commission's Palliative Care Interdisciplinary Advisory Council (PCIAC), charging the Council with assessing and defining relevant clinical, system, educational and policy issues regarding the availability of supportive palliative care in Texas along with promoting professional and public education about palliative care in order to enhance Texans' awareness and access to high-quality and continuously improving palliative care services. Patients, families, caregiver teams and health care clinicians would be educated and have access to supportive palliative care specialist which provide gold standard and evidenced specialty care through a specialty trained and educated interdisciplinary healthcare professionals. To fulfill those charges, the Council has published three biennial reports in 2016, 2018, and 2020; and now submits this 2022 fourth report to update, inform and advise the Commission, the Governor, and the 88th Legislature.

The Council's initial 2016 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 and hospice websites 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

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 spurred favorable statewide discussion among healthcare professionals and positioned Texas as a leader in this growing national trend.

In the second biennial report in 2018, the Council recommended 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, the Council continued emphasis on Advance Care Planning which is paramount to helping palliative care services meet the individual and personal expressed needs of patients and families. That report summarized efforts and progress of the Council's efforts and delineated recommendations for further advancements that were then accomplished:

- Adopted statutory language for Supportive Palliative Care
- Prioritized Advance Care Planning
- Addressed palliative care provider shortages
- Expanded Supportive Palliative Care programs as a Value-Based Model
- Established a statewide palliative care dashboard
- Supported a balanced response to the opioid crisis

The third biennial report released in 2020 summarized continued efforts and progress over the interim since the previous report, built upon the foundational efforts documented in the first three reports, created a new pediatric sub-committee and delineated recommendations for further advancements, including the following policy issues:

Policy Issue: Enhancing Family Caregiver Support
Policy Issue: Adoption of a Medicaid Supportive Palliative Care Benefit
Policy Issue: Utilizing Telemedicine for Supportive Palliative Care
Policy Issue: Amending the language around House Bill 3703 to change eligibility requirements for the use of low-THC cannabis for cancer patients

This fourth report focuses on specific areas of need and interest in the field of SPC in Texas. The following policy issues include:

Policy Issue: Supportive Palliative Care Regulatory Standards for Home Health Agencies
Policy Issue: Adoption of a Texas Medicaid Advance Care Planning Benefit
Policy Issue: Child Life Specialists are Essential Members of the Supportive Palliative Care Team
Policy Issue: Promote Health Care Provider and Health Care Professional Continuing Education Opportunities
Policy Issue: Establishment of a Supportive Palliative Care Awareness Day
Policy Issue: Expanding the Medicaid Hospice Benefit into the Prenatal Period to Improve Care for Children with a Terminal and/or Life-Limiting Illness

As the volume in Texas health care needs continue to escalate in parallel with primary, specialty and serious and often life limiting illness, Council encourages the Texas legislature to utilize all available human capital to their full extent of education, training, licensure and certification thereby increasing access to high quality and affordable health care across the settings and life continuum. Texas has a unique opportunity to improve the quality of life for some of the most vulnerable patients and improve healthcare workflow in the upcoming 88th legislative session. When patients are aware and afforded early access to evidenced based SPC the benefits to the patient, family, caregiver, health care teams and health care systems are tremendously positive. When patients have the right care, at the right time, for the right reason, everyone positively benefits.

The Council has invested extensive thought and deliberation into the "Why?" and "How?" of these issues, and those considerations are detailed in the considerations below. The outlined recommendations of the Council offer good faith solutions reflecting expert specialists and multiple stakeholders efforts in advancing supportive palliative care closer to a goal where all Texans who are facing serious illness have the information, education and opportunity to choose specialty care most congruent with the desired patient centered goals of care and values; and, this care is provided through the highest possible quality and evidenced based specialty and interdisciplinary care. The Council offers thoughtful considerations about appropriate supportive palliative care in the settings across 254 counties,

requiring conscientious efforts by specialty healthcare professionals and systems along with prudent public policy to ensure that this specialty health care service line and resources are being provided to patients and caregivers enduring serious illness.

Since 2015, Texas has seen substantial growth in numbers of Texans suffering from serious illness and in need of care in addition to an accelerating healthcare professional workforce electing to focus on the supportive palliative care specialty to assist in filling the gaps of care across the in and out-patient settings. The work of this Council has been integral to the multifaceted enhancement of primary and specialty supportive palliative care across Texas, as we endeavor to advance Texas as a model of excellence and evidenced based specialty care in and out of Texas. The following discussion and recommendations outline the expert collaboration and consensus across health care clinicians and professionals of the Council.

The Council offers this report for thoughtful review and reflection, and for sound consideration of the recommendations put forward. Please contact us any time for any further clarification and discussion on these solutions to help vulnerable and at-risk Texans and those which help care for them.

Sincerely,

Dr. Erin Perez

Erin Perez, DNP, APRN, ANP-C, AGNP-C, ACHPN
Chair, Palliative Care Interdisciplinary Advisory Council

2. About the Palliative Care Interdisciplinary Advisory Council

House Bill (HB) 1874, 84th Legislature, Regular Session, 2015, established the Palliative Care Interdisciplinary Advisory Council (PCIAC).[1] 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:

- 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;
- 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
- Pursues other deliverables consistent with its purpose as requested by the Executive Commissioner or adopted into the work plan or bylaws of the Council.
- Hosts Annual Continuing Education (CE) Events. This aim is imperative to the purposes of the PCIAC. Since 2017, CE events have been held annually and developed to award CE credits to interdisciplinary professionals on current topics for palliative care and include ethics credits.
- Implementing Senate Bill (SB) 916, 86th Texas Legislature, 2019 which requires an assessment of the potential improvements of supportive palliative care (SPC) on health quality, health outcomes, and cost savings from the availability of SPC services in Medicaid. Additionally, the study will include an evaluation and comparison of other states that provide Medicaid reimbursement for SPC.

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[1] 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

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. Erin Perez, DNP, APRN, ANP-C, AGNP-C, ACHPN serves as the current chair of the Council. The current vice-chair is Hattie Henderson, M.D., CMD. The Council also includes ex officio, non-voting representation from HHSC.

Voting Members

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Houston, Texas

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The University of Texas M.D. Anderson Cancer Center
UT Distinguished Teaching Professor
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Ex Officio Member

Karen Hardwick, Ph.D.
Coordinator, Specialized Therapies
Health and Human Service Commission
Austin, Texas

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.

Supportive Palliative Care (SPC) is not end of life care. SPC offers specialized, multi-disciplinary support to relieve a patient's symptoms, pain, and stress at any stage of a life-threatening illness. While hospice care (HC) helps patients in the terminal stage of serious and life limiting illness, supportive palliative care is most effective when started on day of diagnosis of serious illness, the earliest part of an individual's overall health care plan. The best available evidence shows that supportive palliative care improves quality of life, reduces patient and caregiver burdens, and lowers medical costs while focusing on patient centered goals of health care.

A seven year review from the inception and from passage of House Bill 1874 (Zerwas) 84th legislative session finds the state advancing in its efforts to increase access to palliative care. Texas has established a central website resource to provide critical information and education to patients, families, and health care professionals and is monitoring relevant indicators of progress and performance.[2] Awareness of the benefits of specialty supportive palliative care and hospice care are on the rise as is the number of multi-disciplinary specialty professionals and inpatient palliative care programs. A standardized definition of supportive palliative care has passed in Senate Bill 916 (Johnson) 86th legislative session, largely as a result of the work of this Council. However, even with this initial momentum, substantial gaps in access to supportive palliative care persist. Specialty teams, professional resources and patient/family benefits 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 supportive palliative care infrastructure.

With this context in mind, the Council releases its fourth biennial report to the Texas Legislature with ideas to improve access to patient and family-centered

[2] Palliative Care. https://www.hhs.texas.gov/services/health/palliative-care

supportive palliative care. The recommendations that follow (see below), all adopted without a dissenting vote in consensus, 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 this specialty care which is congruent with the patient desired goals, wishes and values which provides evidenced based and gold standard supportive palliative care.

Recommendations

Supportive Palliative Care Standards for Home Health Agencies

1. Texas home health agencies should employ SPC interdisciplinary teams that include an essential core team composed of a prescribing clinician (physician, advanced practice provider [advanced practice registered nurse (APRN) or physician assistant (PA)]) and registered nurse, a licensed clinical social worker and a chaplain. Other individuals who enhance the quality of life for both the SPC patient and family should be employed as part of the team on an as-needed basis and include pharmacists, physical/speech/occupational therapists, child life specialists, nutritionists, psychologists, etc. Texas home health agencies that provide care to only pediatric patients should employ a child life specialist as part of the core SPC team.
2. Texas home health agencies should also set minimum qualifications for their providers. This should include encouraging that physicians and APRNs be board certified in hospice and palliative care and/or have a Hospice Medical Director certification and/or have 12 hours of continuing education in hospice and palliative care related topics in the first year with a minimum of two hours of additional continuing education per year for subsequent years. Currently PAs do not have a national specialty board certification available. Other core team members should also be encouraged to have additional certification in hospice and palliative care for their specific discipline and role. Texas home health agencies should also encourage that their employed providers on the SPC interdisciplinary team complete at least four hours in hospice and palliative care continuing education topics per year. These topics include specialty pain and symptom management, nutritional support, medication management in addition to non-pain symptom management, end of life care, spiritual care, complex communication for serious and life limiting illness and advance care planning. Texas Home health agencies should also develop guidance on evidence-based standards of care and quality metrics

for SPC based on the National Quality Forum Palliative and End of Life practice guidelines and implement all eight domains.[3]

Adoption of a Texas Medicaid Advance Care Planning Benefit

1. Texas Medicaid should adopt an advance care planning (ACP) benefit that provides reimbursement for vital and ongoing crucial ACP discussions to be provided in-person and/or via telehealth. Texans should have ongoing communication and discussion through their health care providers to have fluid and flexible dialogue on what matters most to them in the current clinical state. Legal guardians, medical surrogates per Texas Hierarchy of Signatures, and those appointed as Medical Power of Attorney (MPOA) for the patient should be included in these conversations whenever possible. Information from ACP conversations should be entered into the patients' health care record during each encounter had with their health care team. In Texas, in order to honor the last known wishes of the patient, written ACP documents must be legally completed for all ACP conversations. It is thought to be best practice to have a treating health care provider follow up on the ACP goals, wishes and values annually as part of their health and wellness care. This can be discussed in primary or specialty care, ideally before the patient becomes incapacitated and in the hospital.
2. Ongoing education and training resources should be made available for complex communications in ACP between the healthcare provider and patient and Council encourage all healthcare providers of the SPC interdisciplinary team (IDT) to conduct these crucial conversations with patients.

Child Life Specialists are Essential Members of the SPC Team

1. All Texas SPC interdisciplinary teams should include educated and trained SPC child life specialists as essential members of the team for both adult and pediatric patients, when deemed necessary. The Texas Legislature should also request HHSC to develop a pilot program to assess potential cost savings that may result from allocating state funds to help establish and maintain CLS positions in inpatient and community-based clinical settings.

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[3] Palliative Care and End-of-Life Care—A Consensus Report. https://www.qualityforum.org/Publications/2012/04/Palliative_Care_and_End-of-Life_Care%e2%80%94A_Consensus_Report.aspx

Promote Provider and Health Care Professional Continuing Education Opportunities

1. Texas should increase access to continuing education opportunities in SPC and hospice related topics for the entire interdisciplinary SPC team which may include physicians, advanced practice registered nurses (APRNs), physician assistants (PAs), nurses, social workers, chaplains, child life specialists and pharmacists. The Texas legislature should appropriate funding to support academic health care facilities and other programs to provide free and low-cost continuing education, training, and certification specialty preparation for hospice and SPC related topics. Providers and health care professionals whose professions have a certificate and/or board certification in SPC and/or hospice care should pursue these educational opportunities ensure gold standard of high quality and evidenced-based specialty care.

Establishment of a SPC Awareness Day

1. Texas should adopt October 10th as Supportive Palliative Care Awareness Day to raise awareness about supportive palliative care optimizing the quality of life and improvement of care for seriously ill patients and their families.

Expanding the Medicaid Hospice Benefit into the Prenatal Period to Improve Care for Neonates with a Terminal or Life-Limiting Illness

Every child and their family deserve individualized, comprehensive, and compassionate care. With an estimated 50% increase in the number of Texas children being born with a terminal or life-limiting illness, the PCIAC strongly recommends the creation of policy and funding initiatives that will increase access to pediatric and perinatal palliative care, including prenatal services. [4,5,6,7,8] Recommended initiatives include the following:

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[4] Schechtman, K., 2002. Decision-making for termination of pregnancies with fetal anomalies: Analysis of 53,000 pregnancies. *Obstetrics & Gynecology*, 99(2), pp.216–222. https://pubmed.ncbi.nlm.nih.gov/11814500/

[5] Bourke, J. et al., 2005. The effect of terminations of pregnancy for fetal abnormalities on trends in mortality to one year of age in Western Australia. *Paediatric and Perinatal Epidemiology*, 19(4), pp.284–293. https://pubmed.ncbi.nlm.nih.gov/15958151/

[6] Western Australia Statistics – births, deaths, and marriages registered. https://www.wa.gov.au/organisation/department-of-justice/the-registry-of-births-deaths-and-marriages/statistics-births-deaths-and-marriages-registered

[7] Texas Health Data, Live Births in Texas, 2005-2019. https://healthdata.dshs.texas.gov/dashboard/births-and-deaths/live-births

[8] Texas Health Data, Deaths (2006-2019). https://healthdata.dshs.texas.gov/dashboard/births-and-deaths/deaths-2006-2019

1. The Texas Health and Human Services Commission (HHSC), working with the Center for Medicare and Medicaid Services and members of the Pediatric Subcommittee of the Palliative Care Interdisciplinary Advisory Council (PCIAC) should make Medicaid State Plan amendments and/or Medicaid waiver requests to:
   a. Expand eligibility for the Medicaid hospice benefit to include prenatal services for pregnant mothers with a child that has been diagnosed with a terminal or life-limiting illness; and
   b. Create special reimbursement classes for the Medicaid hospice benefit that can be used in research and demonstration projects intended to improve access to hospice and supportive palliative care services.
2. With funding appropriated by the Texas legislature, a state-wide pediatric palliative care network should be created based on the Texas Child Psychiatry Access Network (CPAN). The network will improve access to pediatric and perinatal palliative care in rural and under-staffed areas by providing provider-to-provider consultations related to specific patients, educational programs, and support to adult-focused programs providing supportive palliative care and hospice services to prenatal and pediatric patients.

3. HHSC should work with key stakeholders to create specific guidance for hospice programs as they fully implement federal concurrent care regulations for pediatric patients, including the enrollment of patients receiving medical care in an acute care hospital if they meet the prognosis criteria.

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 challenges in ongoing misunderstandings by health care clinicians and consumers that supportive palliative care is synonymous with end-of-life, hospice care. Supportive Palliative Care is not intended to replace hospice specialist which provide end of life care. It offers specialized, multidisciplinary support to relieve a patient suffering with a serious illness of physical, emotional and spiritual burdens at any stage of a life-threatening illness. While hospice palliative care helps patients in the terminal stage of serious illness (six months or less prognosis), SPC is most effective when started early as part of an individual's overall collaborative health care plan A growing body of evidence shows that SPC improves quality of life, reduces patient and caregiver burdens, and improves health care fiscal stewardship. SPC may be combined with attempts of curative and disease modifying treatments which extend life or promote recovery from serious illness. The Council's second report addressed increasing the availability of patient and family focused SPC in Texas with an emphasis on advance care planning. The Council also recommended and was successful in helping to develop statutory language for SPC enacted into law by the Texas Legislature in Senate Bill 916 (Johnson) in the 86th legislative session. The Council's third report included guidance for enhancing caregiver support, proposed the adoption of a Medicaid supportive palliative care benefit, advocated for increasing utilization of tele health/telemedicine for SPC, and promoted changing eligibility requirements for the use of low-THC cannabis for cancer patients. This fourth report will highlight recommendations that set SPC standards for home health agencies, advocate for the adoption of a Texas Medicaid advance care planning benefit, endorse child life specialists as essential members of the SPC team, promote provider and healthcare professional continuing education opportunities, advocate for the establishment of a SPC awareness day in Texas, and promote the expansion of the Medicaid hospice benefit into the prenatal period to improve care for children with a terminal or life-limiting illness.

Since inception in the 84th legislative session, the Council has collaborated with the state's Palliative Care Information and Education program to catalyze a sustained quality improvement effort which aims to advance evidenced based SPC across Texas and further endeavor in cultivating Texas as a national SPC leader for

providing appropriate, compassionate, and high-quality SPC to patients and families at any stage of serious illness. To date, significant activities and accomplishments from this endeavor include:

- Publishing three inaugural legislative reports,[9] and now a fourth report;
- Launching the first Texas Health and Human Services (HHS) system palliative care website resource for patients, families, and professionals;[10]
- Developing, conducting, and supporting annual palliative care continuing education events starting in 2017, awarding about 1500 continuing education hours to date for interdisciplinary professionals;
- Establishing methods to track and report on key measures of supportive palliative care access;
- Advancing a statewide, population-based data collection initiative to assess completion of advance care planning documents in Texas;[11] and
- Elevating the profile of serious illness care as a significant area of opportunity for raising overall healthcare quality of at risk and vulnerable Texans.[12]

In its initial assessment, the Council concluded that the available evidence supported the Legislature's belief, as described in HB 1874, that broad advances in access to palliative care are possible in Texas. Most recently, the Council was charged with aiding HHSC in implementing Senate Bill (SB) 916, 86th Texas Legislature, Regular Session, 2019. This bill authorized HHSC to conduct a study to assess the potential improvements of SPC on health quality, health outcomes, and cost savings from the availability of SPC services in Medicaid. Additionally, the Council aided in the development of a study that included an evaluation and comparison of other states that provide Medicaid reimbursement for SPC. Study findings were submitted to the Council on September 1, 2022, and findings from the study are detailed later in the report.

In 2018, HHSC added two questions to the Behavioral Risk Factor Surveillance System (BRFSS) as part of a statewide, population-based data collection initiative to assess completion of advance care planning documents in Texas. Tables 6-11

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[9] Texas Palliative Care Interdisciplinary Advisory Council (November 2018). Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 86th Texas Legislature. Retrieved from https://hhs.texas.gov/sites/default/files/documents/laws-regulations/reports-presentations/2019/tpiac-recs-86th-leg-nov-2018.pdf

[10] Texas Health and Human Services Webpage on Palliative Care. https://hhs.texas.gov/services/health/palliative-care

[11] 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

[12] 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

contain the data and can be found in the appendix. The weighted data that were analyzed focused on adults 65 and older living in Texas. The two “yes or no” response questions used to assess the completion of advanced care planning were, “Do you have a written advance directive” and “If a terminal illness or serious accident left you unable to communicate, would a family member, friend, doctor, or other person know your medical or health care treatment preferences?” Based on analysis of the survey results, we found that the data showed concerning results.

Only about half (51%) of Texans aged 65 and older said that yes, they have a written advance directive. Among those individuals reporting a disability, fewer than half (47%) had completed an advance directive. Additionally, of the estimated population ever diagnosed with a chronic condition or serious illness risk factors, a small majority said they had written advance directives (52% any chronic condition, 57% cancer, 59% heart disease, 59% cardiovascular disease, and 45% diabetes).

Clear differences also are evident by demographics and geography. Survey estimates indicate that 61% of White, Non-Hispanic individuals have a written advance directive while only 38% of Black individuals and 31% of Hispanic individuals do. Additionally, females are more likely than males to respond yes to having written advance directives (55% vs 46%). Regarding geographical variation, the highest response for yes was in Regions 1 & 2 (Panhandle/North Texas) at 63% and Region 7 (Central Texas) at 57% with the lowest rate of yes responses in Region 8 & 11 (South Texas) at 45%. These discrepancies point to a need for greater education and awareness on the importance of completing written advance directives for certain geographical regions, males, and Black and Hispanic individuals. Please note that some neighboring public health regions were combined to obtain more reliable estimates.

It is important to have an advance directive in the event that an individual no longer has the mental or physical capacity to speak for themselves on decisions regarding their health. Having a written advance directive allows an individual to create written, legal instructions 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 unnecessary suffering and relieve caregivers and loved ones of decision-making burdens during moments of crisis or grief. Therefore, advance directive discussions should occur when a patient is not ill or when his or her symptoms are under reasonable control.

Fortunately, results were more promising when respondents were asked, “if a terminal illness or serious accident left you unable to communicate, would a family member, friend, doctor or other person know your medical or health care treatment preferences?” About 83% of respondents reported that a person would have

knowledge of their preferences, indicating that a large majority of Texans have at least had conversations with someone they trust about their medical care preferences in the event that they are unable to communicate for themselves. However, similarly to the survey question about written advance directives, a higher rate of females than males said yes regarding knowledge of their medical preferences (85% vs 79%) and more White individuals said yes than Black or Hispanic individuals (88% vs 66% vs 75%). In addition, regional variation is evident in the survey results, indicating that survey respondents from metropolitan statistical areas were more likely to have responded yes to having a conversation with someone about their medical care preferences (85% vs 74%). Regarding geographical variation, the highest estimates for yes were in Regions 1 &2 (Panhandle/North Texas) at 91% and Region 3 (Northeast Texas) at 89% with the lowest estimates for yes in Region 4 & 5 (East Texas) at 74% and Region 7 (Central Texas) at 77%. This further illustrates the need for providing greater education and awareness on the importance of completing advance care planning, with a greater focus towards certain geographical regions (including rural areas), males, Black and Hispanic individuals.

Over the past seven years, indicators of SPC access tracked by the Council have shown improvement. A national leader in SPC, The Center to Advance Palliative Care (CAPC) publishes national and state level results or "grades" to provide an analysis of whether patients living with a serious illness in the United States are receiving equitable access to palliative care services in hospitals. These CAPC results are only published periodically, so the Council requested that HHSC staff also 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 the Texas staff largely corroborated the earlier CAPC results for the state and have followed emerging trends through 2020 to report this "in-house" Texas data (see Table 1). CAPC's most recently published results used 2017 data. The CAPC results show that from 2012/2013 to 2017, 20 Texas hospitals added a palliative care program, and the state CAPC rate stands at 52%. Nevertheless, despite the gains, the Texas CAPC rate in 2017 still trailed the 2017 CAPC national rate by 20 percentage points. The Texas in-house data shows that from 2014 to 2020, the grade went from 42% to 52%, a significant improvement for Texas.

Table 1. In-House Texas vs. CAPC Grades, Total Palliative Care Programs Among Hospitals with 50 and 300 or more Staffed Beds

Source	Data Year	Grade	Total Programs/ Hospitals (≥ 50 beds)	Grade	Total Programs/ Hospitals (≥ 300 beds)
CAPC National	2012/ 2013	67%	(1,591/2,393)	90%	(659/732)
CAPC National	2017	72%	(1,723/2,409)	93%	(671/716)
CAPC Texas	2012/ 2013	43%	(85/198)	66%	(37/56)
CAPC Texas	2017	52%	(105/201)	75%	(46/61)
In-house Texas	2014	42%	(87/208)	71%	(42/59)
In-house Texas	2015	46%	(97/210)	71%	(41/59)
In-house Texas	2016	49%	(101/205)	74%	(46/62)
In-house Texas	2017	50%	(102/206)	75%	(47/63)
In-house Texas	2018	49%	(100/204)	75%	(46/61)
In-house Texas	2019	51%	(101/198)	79%	(50/63)
In-house Texas	2020	52%	(102/198)	81%	(52/64)

Note: Results are based on the CAPC defined hospital cohort. 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. [13] Results from previous years of in-house Texas data have slightly changed due to a minor change in methodology of calculating results.

[13] Veterans Administration and Indian Health Service facilities were excluded. CAPC does not clearly distinguish hospital run palliative care programs from contracted services. Data collected from: https://reportcard.capc.org/wp-content/uploads/2020/05/CAPC_State-by-State-Report-Card_051120.pdf

Figure 1. Texas Palliative Care Programs by Public Health Region (PHR), 2020

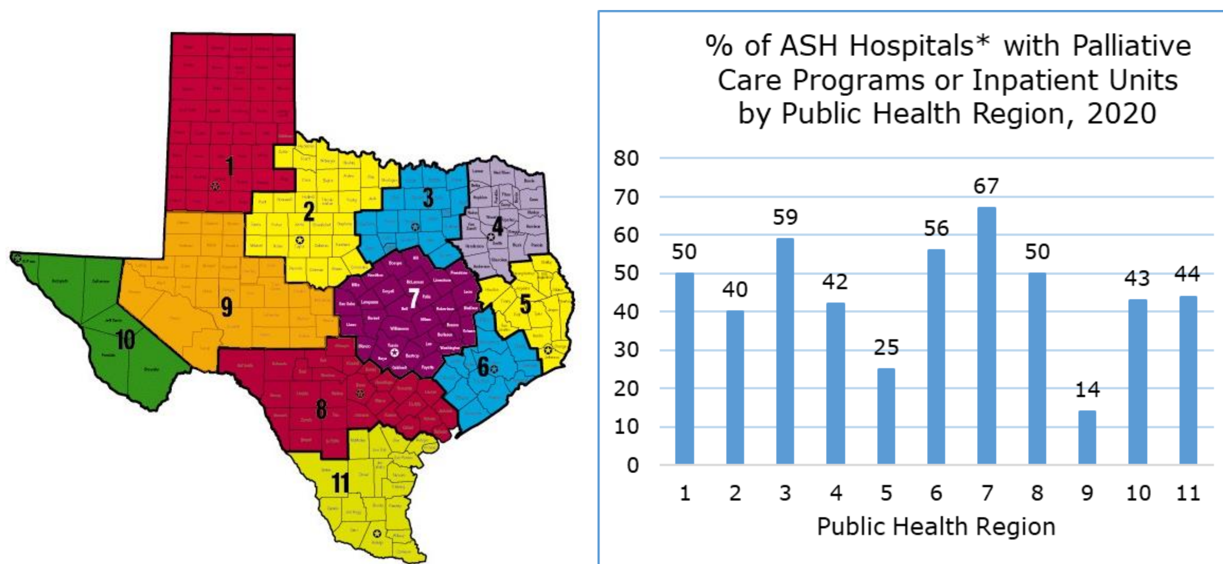

Table 2. Texas Palliative Care Programs by Public Health Region (PHR), 2020[14]

PHR	# Hospitals (50 or more beds)	# with PC Program	% with PC Program
1	8	4^	50%
2	5	2	40%
3	59	35**	59%
4	12	5*	42%
5	8	2^	25%
6	39	22***	56%
7	21	14^	67%
8	16	8	50%
9	7	1^	14%
10	7	3*	43%
11	16	7*	44%
Total	198	102	52%

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

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[14] Note: PHRs denoted with one asterisk (*) gained one palliative care program or inpatient unit. between 2018 and 2020; PHR 3 denoted by (**) gained two programs, and PHR 6 by (***) gained three programs. PHRs denoted by (^) lost one palliative care program or inpatient unit. The number of programs in other regions remained the same though the total number of hospitals may have changed.

community. As shown above (Figure 1), a much lower percentage of hospitals in Public Health Region (PHR) 4 (East Texas), PHR 9 (West Texas), and PHR 10 (West Texas) offer palliative care services than hospitals in other parts of the state. While most regions clearly trail the nation, PHR 1 (Panhandle) has a rate that is above the national average and PHR 7 (Austin/Central) also shows a relatively high performance. However, both regions lost one hospital program from 2018 to 2020, including PHR 5 and PHR 9 (Table 2). Other regions adding programs include PHR 3 (Dallas) with two, and PHR 4 (East Texas) with one, PHR 6 (Houston) with three, PHR 10 (West Texas) with one, and PHR 11 (Rio Grande Valley) with one.

As with hospitals, more interdisciplinary professionals are entering the field of palliative care (Table 3). Between 2015 and 2021, Texas physicians with a hospice and palliative medicine (HPM) specialty increased by 112%, including a 169% jump for doctors listing HPM as their primary specialty; certified Advanced Practice Registered Nurses increased from 2015 to 2022 by 152%; Certified Hospice Medical Directors increased from 2015 to 2022 by 211%; and palliative medicine fellows increased from 2015 to 2021 by 68%.

Table 3. Growth by Palliative Care Profession, Texas, 2015 – Current Number

Professional Category	Number 2015	Number 2017	Number 2019	Current Number	% Increase from 2015 – Current Number
Physicians with Palliative Specialty	275	332	379	583 (2021)	112%
Primary	51	78	89	137 (2021)	169%
Secondary	224	254	290	446 (2021)	99%
Certified APRN	46	73	95	116 (2022)	152%
Certified Hospice Medical Director	19	26	47	59 (2022)	211%
Palliative Medicine Fellow	19	26	28	32 (2021)	68%

Note: Palliative Medicine Fellow data for all years has been updated to reflect revised numbers.
Source: Health Professions Resource Center, Center for Health Statistics, DSHS.

Table 4. Physicians with Primary or Secondary Specialty in Hospice and Palliative Medicine (HPM), by Public Health Region (PHR), 2015 - 2021

PHR	# HPM Physicians 2015	# HPM Physicians 2017	# HPM Physicians 2019	# HPM Physicians 2021	# per 100,000 population (age 18 years and older), 2021	# per 100,000 population (age 65 years and older), 2021
1	9	12	11	24	0.1	0.59
2	7	8	10	11	0.05	0.27
3	62	77	97	154	0.68	3.78
4	12	16	14	20	0.09	0.49
5	10	15	15	15	0.07	0.37
6	74	89	98	148	0.66	3.63
7	41	46	51	81	0.36	1.99
8	36	39	51	91	0.40	2.23
9	11	9	8	9	0.04	0.22
10	3	4	5	7	0.03	0.17
11	10	17	19	23	0.10	0.56
Total	275	332	379	583	2.6	14.31

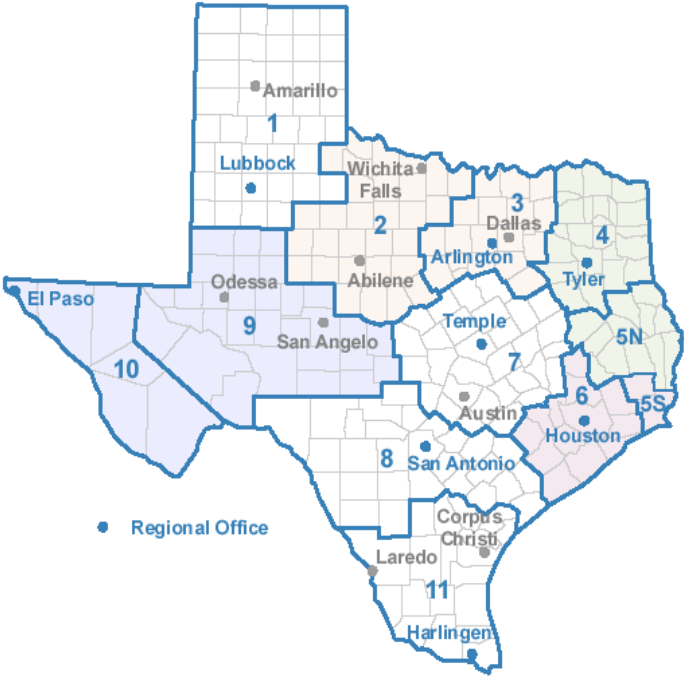
Source: Health Professions Resource Center, Center for Health Statistics, DSHS

Table 5: Number of Hospice and Palliative Credentialing Center (HPCC) certificates for advanced certified hospice and palliative nurses (ACHPNs) in Texas, by Public Health Region (PHR), 2020-2022

Public Health Region	Total number of HPCC certificates 2020	Total number of HPCC certificates 2021	Total number of HPCC certificates 2022
1	5	5	5
2	4	4	6
3	16	16	17
4	3	4	4
5	0	0	0
6	31	30	33
7	26	31	35

Public Health Region	Total number of HPCC certificates 2020	Total number of HPCC certificates 2021	Total number of HPCC certificates 2022
8	12	7	7
9	4	4	4
10	1	1	1
11	4	3	4
Total	106	105	116

Source: Hospice and Palliative Care Nurses Association



The increase in palliative care workforce is broadly distributed across Texas (Table 4). Only one region, the rural region of PHR 9 (West Texas)) experienced a decline in palliative care physicians. Two regions with significant needs, PHR 2 (North Central Texas) and PHR 10 (West Texas), saw positive growth in HPM specialists relative to 2017.

Additionally, Table 5 shows the geographic distribution of the number of Texas Advanced Practice Registered Nurses (APRNs) who have become nationally boarded as advanced certified hospice and palliative nurses (ACHPNs). The national board

certification is from the Hospice and Palliative Credentialing Center (HPCC). Overall, the extraordinary 152% growth in certified APRNs seen from 2015-2022 provides insight that APRNs have recognized the heath care needs for some of the most vulnerable and at-risk Texans and are joining in efforts to help bridge the health care gap for supportive palliative care patients and families in Texas. There remain barriers to allowing health care providers to practice to the fullest extent of their education, training, licensure and certification remain a challenge to health care access at this time. In previous legislative reports this Council has made and supported removing barriers to practice in efforts to improve access to high quality health care professionals and make efforts to improve the overall health and quality of life of Texans and the health care system caring for them.

Even with this initial progress, the Council recognizes that substantial gaps in health care persist. Specialty teams, professional resources and funding for SPC remain below national rates found in most other states, and, as leading experts point out, demand for patient-centered and family-focused specialty SPC continues to grow exponentially.[15] Texas still faces notable challenges to expand the availability of SPC 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 SPC infrastructure.

Over the past six years, the Council has heard from a wide variety of healthcare professionals, subject matter experts, and stakeholders and reviewed a wide array of research and literature to create the recommendations discussed in this report. The report sets SPC standards for home health agencies, advocate for the adoption of a Texas Medicaid advance care planning benefit, endorse child life specialists as essential members of the SPC team, promote provider and health care professional continuing education opportunities, advocate for the establishment of a SPC awareness day in Texas, and promote the expansion of the Medicaid hospice benefit into the prenatal period to improve care for children with a terminal or life-limiting illness.

The recommendations that follow, all adopted with no dissenting votes and in consensus 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

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[15] 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). https://pubmed.ncbi.nlm.nih.gov/29410071/

information and opportunity to choose specialty care that is most congruent with the patient centered goals of care and values.

6. Recommendations Based on Senate Bill 916 Report Findings

SB 916, 86th Texas Legislature, Regular Session, 2019, authorized the Health and Human Services Commission (HHSC) to conduct a study to assess potential improvements to a patient 's quality of care and health outcomes and to anticipated cost savings to this state from supporting the use of or providing Medicaid reimbursement to certain Medicaid recipients for supportive palliative care.[16] The study also included an evaluation and comparison of other states that provide Medicaid reimbursement for supportive palliative care. The final report was submitted to the PCIAC for incorporation of the findings into this legislative report.

Findings from State Medicaid SPC Programs

To summarize the findings from the SB 916 report, most states with a Medicaid SPC benefit developed standardized definitions of SPC and established specific eligibility criteria. Many states with a SPC Medicaid benefit also provide a comprehensive set of SPC services based on national consensus guidelines which are delivered by a trained specialty interdisciplinary team in a variety of service delivery settings.[17] Some states, such as Arizona and California, have utilized pre-existing billing codes in their Medicaid programs to support the array of SPC services they offer. Additionally, some states have incorporated SPC into their quality improvement initiatives to monitor access to and the quality of palliative care services being provided. It was also noted that all states with a state Medicaid SPC program reimburse for ACP. The report also indicated that several states promote the advancement of SPC by encouraging health care providers to pursue continuing specialty education and share palliative care related information with consumers and non-specialty SPC health care professionals. Some states also promote public awareness and education initiatives and have state legislation requiring public health agencies to develop and disseminate resources about SPC and through the establishment of state supported councils or task forces.

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[16] Senate Bill 916, 87th Texas Legislature, 2021.
https://capitol.texas.gov/tlodocs/86R/billtext/pdf/SB00916F.pdf#navpanes=0
[17] Clinical practice guidelines for quality palliative care. NCHPC.
https://www.nationalcoalitionhpc.org/wp-content/uploads/2020/07/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf.

Findings from Quality Improvement and Cost-Savings Analysis

The SB 916 report also detailed important findings from data analytics that were performed to identify potential quality improvement and cost-savings opportunities in Texas from supporting the use of SPC services.

In the report, Texas performed data analytics to identify which chronic conditions were most common among decedents, or individuals who have died, in the Texas Medicaid and the Medicare-Medicaid Plan (MMP) populations that would be most likely to benefit from SPC services. While some chronic conditions were identified as more prevalent among this population than others, experts on the PCIAC agreed that all beneficiaries with any of the eight leading chronic conditions could benefit from being provided SPC services. These chronic conditions included chronic kidney disease, heart failure/ischemic heart disease, diabetes, chronic obstructive pulmonary disease (COPD), liver disease/other liver conditions, Alzheimer's disease/related disorders or senile dementia, stroke, and cancer (breast, colorectal, endometrial, lung, prostate).

Additional analysis identified in the SB 916 report showed that inpatient hospital (IP) stays and emergency department (ED) utilization was much higher for Texas Medicaid decedents with the top eight chronic conditions than for all other decedents, especially from the 12-month period prior to death. For individuals with a high chronic disease burden, SPC services can help manage symptoms and thereby reduce the number of IP stays and ED visits, especially when utilized earlier in a patient's serious illness disease progression prior to end of life during the period of hospice eligibility or brink of death.[18] Improvements in patient quality of care from the use of SPC services could prevent unnecessary IP stays and ED visits, therefore providing anticipated cost savings. Additional analysis showed that Medicaid decedents with any of the top eight chronic conditions had a higher number of IP stays as well as a longer length of stays than for all other decedents without these conditions. Providing SPC services to patients has been shown to reduce length of stay, decrease non-beneficial health care, improve patient desired focus of health care, and provide cost savings and improved quality metrics.[19]

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[18] Spilsbury, K., Rosenwax, L., Arendts, G., & Semmens, J. B. (2017). The impact of community-based palliative care on acute hospital use in the last year of life is modified by time to death, age and underlying cause of death. A population-based retrospective cohort study. PloS one, 12(9), e0185275. https://doi.org/10.1371/journal.pone.0185275
[19] May, P., Garrido, M. M., Cassel, J. B., Kelley, A. S., Meier, D. E., Normand, C., Smith, T. J., & Morrison, R. S. (2017). Cost analysis of a prospective multi-site cohort study of

SB 916 report also described how value-based payment strategies can be utilized to promote SPC by developing alternative payment model (APM) arrangements or providing other incentives to promote the formation of new SPC teams in hospitals or community settings. Value-based strategies can also encourage increased completion of ACP documents for individuals of all ages. ACP documents, such as an Advanced Directive and Medical Power of Attorney, help ensure that a patient's wishes are known in the event the individual loses medical decision-making capacity and can guide a patient's caregiver, medical surrogate, legal guardian, and health care team during stressful situations of medical decline. For patients with serious and life limiting illness, early conversations about goals of care are associated with improved patient and family outcomes, reduced use of undesired and nonbeneficial medical care, and reduced costs.[20] The report also provided information about how state Medicaid SPC programs could improve quality and value by financially incentivizing hospitals, MCOs, and other community based SPC programs for meeting certain quality standards of the Joint Commission or other palliative care certifying bodies.

PCIAC Recommendations to Texas Based on Findings

Based on the findings of the SB 916 report, and the recommendations from the previous 2020 PCIAC legislative report, the PCIAC recommends that Texas adopt a Medicaid SPC benefit for individuals of all ages with a serious illness who have at least one of the following eight conditions:

- Chronic kidney disease
- Heart failure/ischemic heart disease
- Diabetes
- COPD
- Advanced liver disease
- Alzheimer's disease or senile dementia
- Stroke
- Cancer

Additionally, findings from the SB 916 report determined that the most common services offered amongst states with a palliative care benefit included advance care

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palliative care consultation teams for adults with advanced cancer: Where do cost-savings come from?. Palliative medicine, 31(4), 378–386. https://doi.org/10.1177/0269216317690098

[20] Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. JAMA Intern Med. 2014 Dec;174(12):1994-2003. doi: 10.1001/jamainternmed.2014.5271. PMID: 25330167.

planning, pain and symptom management, and care coordination or case management. Most states also delivered these services in the inpatient, outpatient, and community settings. SPC services to be offered under a Texas Medicaid SPC benefit should include the following services.

1. Supportive Palliative Care Assessment and Consultation: Consultation includes the collection of patient data and assessment of patient needs.
2. Advance Care Planning: Advance care planning includes the completion of all five Texas legally recognized documents: advanced directive, in and out of hospital do not resuscitate forms, disposition of remains, durable power of attorney and medical power of attorney.
3. Plan of Care/Goals of Care: SPC plan of care includes plans for symptom management, attempts at disease modifying health care interventions, and supportive interventions only if or when life prolonging interventions are no longer desired by and/or are non-beneficial for the patient. The aim is to help and not hurt the patient by the intent of health care interventions for the patient and not to the patient.
4. Interdisciplinary Palliative Care Team: This is a health care team that collaborates to meet the physical, medical, psychosocial, emotional, and spiritual needs of patients and their families and are able to assist in identifying sources of suffering and provide appropriate specialty solutions to ease the symptom burdens.
5. Care Coordination: A member of the palliative care team helps coordinate and implement the patient’s plan of care desired.
6. Pain and Symptom Management: Services used to reduce pain and other symptoms of serious illness including but not limited to shortness of breath, nausea, fatigue and more. The services may involve nursing care, medications, physical and occupational therapy, nutritional support, emotional and spiritual support, and more.
7. Mental Health and Medical Social Services: Counseling to reduce stress, depression, anxiety, and other psychological problems associated with serious illness.
8. Training and Respite Services for Family Caregivers: Training and respite services help to reduce caregiver burnout and caregiver illness.
9. Telehealth Services: Telemedicine and telehealth can be used to minimize the burden on the patient.

SB 916 report findings also displayed that several states with a SPC program have an interdisciplinary team composition consisting of at least one prescribing clinician (physician, APRN, PA), registered nurse, licensed social worker, and spiritual advisor. In the PCIAC's 2020 legislative report, the PCIAC endorsed an interdisciplinary team composition to include, but not be limited to, a prescribing healthcare clinician (physician, advanced practice registered nurse, physician assistant, a registered nurse or license vocational nurse, a social worker, a chaplain/spiritual advisor, and any other individuals or professionals who can enhance the quality of life for both the SPC patient and his/her family (pharmacist, physical/speech/occupational therapist, child life specialist, nutritionist, psychologist, etc.). The council recommends that these individuals, in addition to child life specialists when deemed necessary, be included as reimbursable providers of a supportive palliative care Texas Medicaid benefit.

To pay for SPC program services, Texas Medicaid should use pre-existing billing codes to reimburse providers for services instead of developing new codes to pay for benefit services. In the SB 916 report, the most commonly used palliative care services and their associated billing codes include: end-of-life counseling (HCPCS S0257); advance care planning (CPT 99497, 99498); home/community interdisciplinary care team consults (CPT 99341, 99350); inpatient/outpatient interdisciplinary care team consults (CPT 99366, 99368); individual, family, marriage counseling in-home (CPT 99510); and respite in-home (HCPCS T1005). The 99497 and 99498 codes are currently used for ACP by Medicare. The PCIAC recommends that Texas follow Medicare regulations related to using 99497 and 99498 to reimburse providers under a new Texas Medicaid SPC benefit. Texas should also provide guidance to providers and explain how to use these codes to better track uptake of these services and support best clinical practices.

Texas uses its Medicaid managed care organizations (MCOs) to deliver services to its Medicaid recipients. Under the PCIAC's proposed Texas Medicaid SPC benefit, Texas should develop and implement quality improvement initiatives that incentivize MCOs to pay for SPC services using value-based payment strategies. According to findings from the SB 916 report, at least five states have embedded palliative care-related metrics or quality improvement initiatives into their state Medicaid programs. The Healthcare Effectiveness Data and Information Set (HEDIS) Care for Older Adults is the most common metric used by other states. This measures the percentage of beneficiaries aged 66 years and older who have the following four services in one measurement year: ACP, medication review, functional status assessment, and pain screening.[21] Texas' Medicaid 1115 waiver

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[21] "Care for Older Adults," National Committee for Quality Assurance. https://www.ncqa.org/hedis/measures/care-for-older-adults/

allows the state to expand Medicaid managed care while preserving hospital funding, provides incentive payments for health care improvements and directs more funding to hospitals that serve large numbers of uninsured patients.[22] The waiver also has a quality improvement component where providers can elect to report on a series of palliative care metrics and earn incentives by reporting on these quality metrics and demonstrating improvement. These metrics include pain assessment, documentation of treatment preferences, documentation of discussion on spiritual/religious concerns, bowel regimen for patients treated with an opioid, dyspnea screening and treatment, hospice admissions of less than three days, and patients who died from cancer not admitted to hospice. A Texas Medicaid SPC benefit should set reporting requirements for the HEDIS Care for Older Adults metric as well as the previously mentioned metrics that are being reported under the DSRIP 1115 waiver to promote high quality care for SPC recipients.

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[22] Texas Health and Human Services Commission. Medicaid 1115 Waiver. https://www.hhs.texas.gov/regulations/policies-rules/waivers/medicaid-1115-waiver

7. Recommendations

Policy Issue: SPC Standards for Home Health Agencies

Texas lacks standardized guidance on how supportive palliative care (SPC) should be delivered by home health agencies. Currently, there are no standards set for home health agencies regarding the SPC interdisciplinary team composition, provider minimum qualifications, or guidance on recommended continuing education content and topics that providers should pursue. Home health agencies also lack guidance on evidence-based standards of care and quality metrics for SPC. National SPC quality resources such as The National Quality Forum (NQF) Clinical Practice Guidelines for Quality Palliative Care, the Center to Advance Palliative Care's Serious Illness Framework, and the Convening on Quality Measures for Serious Illness Care have developed robust resources.[23,24,25] Providing standardized guidance and a recommended set of quality metrics for SPC would help ensure that all home health agencies are providing gold standard SPC with high quality and evidenced-based SPC services to all patients they serve.

Recommendation

Texas home health agencies should employ SPC interdisciplinary teams that include an essential core team composed of a prescribing clinician (physician, advanced practice provider [advanced practice registered nurse (APRN) or physician assistant (PA)]), a registered nurse, a licensed clinical social worker and a chaplain. Other individuals who can enhance the quality of life for both the SPC patient and family should be employed as part of the team on an as-needed basis and include pharmacists, physical/speech/occupational therapists, child life specialists, nutritionists, psychologists, etc. Texas home health agencies that provide care to only pediatric patients should employ a child life specialist as part of the core SPC team.

Texas home health agencies should also set minimum qualifications for their providers. This should include encouraging that physicians and APRNs be board

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[23] NQF: Palliative Care and End-of-Life Care. (n.d.). Palliative care and end-of-life care. https://www.qualityforum.org/projects/palliative_care_and_end-of-life_care.aspx
[24] Palliative Care| Center to Advance Palliative Care (2020). Serious illness quality alignment hub. https://www.capc.org/toolkits/serious-illness-quality-alignment-hub/
[25] Quality Measurement and accountability for community- based serious.(2017). https://www.moore.org/docs/default-source/default-document-library/quality-measurement-and-accountability-for-community-based-serious-illness-care-final9a270561a10f68a58452ff00002785c8.pdf?sfvrsn=cb286d0c_0

certified in hospice and palliative care and/or have a Hospice Medical Director certification and/or have 12 hours of continuing education in hospice and palliative care related topics in the first year with a minimum of two hours of additional continuing education per year for subsequent years. Currently PAs do not have a national specialty board certification available. Other core team members should also be encouraged to have additional certification in hospice and palliative care for their specific discipline and role. Texas home health agencies should also encourage that their employed providers on the SPC interdisciplinary team complete at least four hours in hospice and palliative care continuing education topics per year. These topics include pain and symptom management, nutritional support, medication management in addition to non-pain symptom management, end of life care, spiritual care, complex communication for serious and life limiting illness and advance care planning. Texas Home health agencies should also develop guidance on evidence-based standards of care and quality metrics for SPC based on the NQF practice guidelines and implement all eight domains.[26]

Discussion

Supportive Palliative Care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating "total suffering" which encompasses physical, emotional, social and spiritual components across the continuum of a patient's serious illness. Its foundation consists of a well-trained and well-supported interdisciplinary team (IDT) that performs comprehensive assessments and develops and implements palliative care plans in coordination with the patient, family, and other health care and community providers. Board certified palliative care specialists have the ability to address to some extent all four components of total suffering, but the best SPC, just like the best hospice care, is team based and provides comprehensive expertise and support to the patient and family. Physicians and advanced practice providers (APRNs and PAs) have the expertise to address the physical and emotional component, pastoral care the spiritual component, social work the social component, and child life the social and emotional component when children are involved. High quality and evidence-based SPC is delivered in an ethical and holistic model of care which centers on respect for patient and family centered care which honors their expressed values, culture, preferences, and goals. The IDT provides holistic patient and family-centered services, collaborates with partner organizations to facilitate and coordinate timely and efficient internal and external care, fosters a positive organizational culture of diversity, equality and inclusivity, strives for continuous evidenced-based quality

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[26] Palliative care and end of life care- a consensus report. (2012). https://www.qualityforum.org/Publications/2012/04/Palliative_Care_and_End-of-Life_Care%e2%80%94A_Consensus_Report.aspx

improvement, and is tailored to address the unique and individual needs of the patient of the high risk and vulnerable patient populations they serve. Home health agencies that employ the IDT team members recommended in this report will be equipped to be able to provide high quality care to seriously ill patients and their families.

Establishing minimum qualifications for home health agency providers is important to ensure safety standards of specialty care for SPC and that patients have a safe baseline of receiving high quality, affordable, accessible, and evidenced-based SPC services. Additional provider certification in hospice and palliative care as well as promoting annual continuing education training ensures that providers and health care professionals are up to date with best practices in the specialty field to best serve their patients. The PCIAC hosts annual continuing education events on various palliative care related topics to provide continuing education credits to interdisciplinary SPC professionals as well as provides palliative care related resources for providers on its website pages.[27,28] National organizations such as CAPC and the Texas Association of Home Care & Hospice also provide information and resources for home health agencies.[29,30]

Texas Home health agencies currently do not have standardized guidance for evidence-based standards of care or quality metrics for SPC that they must report on. To help home health agencies gauge their progress and ensure that patients are being provided high-quality care, these agencies should follow the NQF's palliative care and hospice framework as well as its recommended performance measures.[31] This framework of preferred practices were derived from the eight domains of quality palliative and hospice care as established by the National Consensus Project for Quality Palliative Care:

- structures and processes of care;
- physical aspects of care;
- psychological and psychiatric aspects of care;
- social aspects of care;

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[27] Palliative care interdisciplinary advisory council.
https://www.hhs.texas.gov/about/leadership/advisory-committees/palliative-care-interdisciplinary-advisory-council

[28] Palliative care for providers. https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers

[29] Tools and training for clinicians: Palliative Care Programs. Center to advance palliative care https://www.capc.org/

[30] Regulations- TAHCH.org (n.d.). Regulations.
https://tahch.org/regulatory/regulatoryinformation

[31] NQF: Palliative care and end of life (n.d.). Palliative care and end-of-life care.
https://www.qualityforum.org/projects/palliative_care_and_end-of-life_care.aspx

- spiritual, religious, and existential aspects of care;
- cultural aspects of care;
- care of the imminently dying patient; and
- ethical and legal aspects of care.

The NQF also recommended that performance measures should be focused on:

- assessment and management of relief of symptoms at EOL and for acutely ill patients (e.g., pain, dyspnea, weight loss, weakness, nausea, serious bowel problems, delirium and depression);
- patient and family centered palliative and hospice care that address psychosocial needs and care transitions; and
- patient, caregiver and family experiences of care.

Policy Issue: Adoption of a Texas Medicaid Advance Care Planning Benefit

Completion of advance care planning (ACP) documents helps ensure that an individual's goals of care, values and treatment wishes are known in a good faith effort to honor them. ACP documents help provide insight, guidance, and clarification should an individual lose medical capacity for decision making. These legal health care documents also help ensure that the treating health care teams are 1) clear on who the patient's selected voice is for health care decision making and 2) what is most important to the patient in clearly documented values and end of life care preferences.

In Texas, there are several ACP legal documents, which include: 1) medical power of attorney (MPOA), 2) advanced directive (AD), 3) in and out of hospital do not resuscitate/intubate forms (OOHDNR), 4) durable power of attorney (DPOA) and 5) disposition of remains. The in-hospital do not resuscitate/intubate must be completed on each admission to the hospital by the attending physician and signed by the patient or medical surrogate per Texas Hierarchy of Signatures or legally completed medical power of attorney.

ACP legal documents completed by the patient prior to losing medical capacity affords the medical decision maker and the health care team a clear perspective on the patients chosen elections in a terminal or irreversible clinical state. The ACP legal documents are only acted on if the patient lacks medical capacity for decision-making. For patients with serious and life limiting illness, early conversations about end-of-life care issues are associated with improved patient health outcomes, including better quality of life, reduced use of undesired and nonbeneficial medical care near end of life, patient health care consistent with patients' values and goals,

improved family outcomes, and reduced utilization and costs.[32] While the importance of ACP has national recognition, studies show that among Americans ages 75 and older, one-in-four say they have not given very much or any thought to their end-of-life wishes and one-in-five say they have neither written down nor talked with someone about their wishes for medical treatment at the end of their lives.[33] Additionally, minority populations and those with lower incomes or education levels are less likely to complete their ACP documents, another important reason for Texas to support provider reimbursement for advance care planning.[34,35] Telehealth is an important tool in service delivery for ACP. The telehealth method can be utilized to facilitate ACP consultations and eliminates barriers such as the need for travel, which can impose a time and financial burden. By allowing telehealth and removing challenges to resources and barriers this improves ACP access and utilization for these crucial conversations that are vital in caring for Texans. The positive ripple effect thereby increases patient access to a provider, overall patient satisfaction, and increases the number of patients who legally complete their ACP documents.[36]

Unfortunately, Texas Medicaid does not currently provide reimbursement for ACP discussions. Texas Medicaid is, however, currently in the process of evaluating ACP as a potential new Medicaid benefit. Codes that are currently under consideration include two Evaluation and Management codes, 99214 (office or other outpatient visit for the evaluation and management of an established patient, 30-39 minutes) and 99215 (40-54 minutes of total time is spent on the date of the encounter) as well as the similar codes 99497 and 99498 which are currently used for ACP by Medicare. Texas should follow Medicaid regulations related to using 99497 and 99498 as part of its proposed ACP benefit. There is consistent evidence that the time spent in counseling a patient and family on their clinical context, review of diagnoses, disease trajectory, options for treatment, and risk vs benefits and alternatives leads to patient centered care. Implementation of patient desired and directed care improves quality of life for the patient, family and health care team

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[32] Bernacki RE, Block SD; American College of Physicians High Value Care Task Force. Communication about serious illness care goals: a review and synthesis of best practices. JAMA Intern Med. 2014 Dec;174(12):1994-2003. doi: 10.1001/jamainternmed.2014.5271. PMID: 25330167.

[33] Pew Research Center. (2013). Views on End-of-Life Medical Treatments. http://www.pewforum.org/2013/11/21/views-on-end-oflife-medical-treatments/

[34] Anne Wilkinson, Neil Wenger, and Lisa R. Shugarman Literature Review on Advance Directives. HHS Office of the Assistant Secretary for Planning and Evaluation, June 2007. http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.pdf

[35] Carr., D. (2011). Racial differences in end-of-life planning: why don't Blacks and Latinos prepare for the inevitable?. Omega (Westport). 2011;63(1):1-20. DOI: 10.2190/OM.63.1.a.

[36] Stinson, Matt, et al. (2019). Compassionate Technology: Palliative Care Telemedicine in the Rural Hospital Setting (QI741). Journal of Pain and Symptom Management 57.2 (2019): 478. DOI:10.1016/j.jpainsymman.2018.12.250

while decreasing associated high cost for nonbeneficial and undesired interventions in a terminal and/or irreversible clinical context.

Recommendation

Texas Medicaid should adopt an advance care planning benefit that provides reimbursement for vital and ongoing crucial ACP discussions to be provided in-person and via telehealth. Texans should have ongoing communication and discussion through their health care providers to have fluid and flexible dialogue on what matters most to them in the current clinical state. Legal guardians, medical surrogates per Texas Hierarchy of Signatures, and those appointed as MPOAs for the patient should be included in these conversations whenever possible. Information from ACP conversations should be entered into the patients' health care record during each encounter had with their health care team. In Texas, in order to honor the last known wishes of the patient, written ACP documents must be legally completed for all ACP conversations. It is thought to be best practice to have a treating health care provider follow up on the ACP goals, wishes and values annually as part of their health and wellness care. This can be discussed in primary or specialty care, ideally before the patient becomes incapacitated and in the hospital.

Ongoing education and training resources should be made available for complex communications in ACP between the healthcare provider and patient and we encourage all healthcare providers of the SPC interdisciplinary team (IDT) to conduct these crucial conversations with patients.

Discussion

Advance care planning for patients includes documented discussions between a provider (MD/DO, APRN or PA) or other qualified healthcare professional and a patient or legal guardian. ACP discussions are not one and done. ACP discussions start with a Goals of Care discussion in which their health care provider reviews the patient and/or legal medical decision makers understanding of the current clinical context (diagnosis, risk versus benefits and alternatives of medically appropriate treatment options and prognosis with and without discussed viable options), explore patient hopes, fears/worries, and what matters most to their values and desires quality of life. Once medical information and dialogue concludes then the patient and/or legal medical decision maker can work through the process of shared decision making with their provider of choice on next steps desired in their chosen health care path. Counseling that takes place during these discussions addresses, but is not limited to, completion of advance directives, MPOAs, durable power of attorney (DPOA), Texas OOHDNRs, in hospital DNR/DNI and disposition of remains. Some health care professionals utilize evidence-based communication tools such as

the Serious Illness Conversation Guide. The ACP process involves four steps: (1) thinking through one's relevant values and preferences, (2) talking about one's values and preferences with one's representative, family members, and health care providers, (3) documenting them with advance directives, and (4) reviewing and updating them periodically.[37] If advance care plans have not been discussed, patients who become incapacitated and lose medical capacity for health care decision making have no control over their medical treatment plan and are more likely to undergo unwanted treatments and tests that are often non-beneficial at end of life, which can cause more hurt than help. Unwanted treatments create an expensive burden not only for patients and families, but also for the health care system. The other side of the burden lies in the emotional toll to family and caregivers, before and after end of life. Many describe ACP as one of the greatest gifts a person can give to their family.

Telehealth should be utilized to facilitate ACP discussions with patients and providers to discuss their serious illness and its impact on values, preferences for health care treatment options, and patient centered goals of care. By encouraging the use of telehealth to conduct ACP consultations, patients have the opportunity to ensure that their goals of life and goals for treatment are understood and clearly documented before a crisis occurs. By adopting a Texas Medicaid benefit for advance care planning that includes telehealth and telemedicine reimbursement for ACP structured similarly to what is now allowed under Medicare, Texas would remove unnecessary barriers and challenges and improve access to this vital service, especially to high risk and vulnerable Texans across 254 counties.

The PCIAC has provided additional information about ACP for patients and healthcare providers, including tools and resources on its HHSC Palliative Care website page.[38]

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[37] AARP Public Policy Institute. (2011). Valuing the Invaluable: 2011 Update– The Economic Value of Family Caregiving in 2009. https://www.caregiver.org/caregiver-statistics-work-and-caregiving
Texas HHSC. (2022). Advance Care Planning. https://www.hhs.texas.gov/providers/long-term-care-providers/nursing-facilities-nf/advance-care-planning#:~:text=Chapter%20166%20of%20the%20Texas%20Health%20and%20Safety,directive.%20Advance%20care%20planning%20is%20a%20five-step%20process.
Perez, E. (2021). Goals, Wishes & Advanced Care Planning. https://nursescarehub.com/education/

[38] Palliative care. https://www.hhs.texas.gov/services/health/palliative-care

Policy Issue: Child Life Specialists are Essential Members of the SPC Team

Each year, more than 500,000 children in the United States cope with life-threatening conditions.[39] Many of these children have a serious, chronically complex and life limiting illness that may require long periods of care beyond the six-month period of hospice eligibility. As of 2010, Section 2302 of the Affordable Care Act (also known as "Concurrent Care for Children") enables children receiving hospice care to receive simultaneous curative treatments.[40] However, children with a serious, chronically complex and life limiting illness, whose life prognosis is beyond the period of hospice eligibility of six months or less, may still benefit from SPC. Evidence is clear and consistent, that when early SPC is delivered by an interdisciplinary team across the patient care settings, patients, families, and the care team all benefit. Patients and families have an additional layer of support aimed to ease their symptom burden, improve quality of life and help their family with complex communication for shared decision-making, symptom management, advance care planning, and emotional and spiritual support for processing and coping. Additionally, many adult patients with a serious, chronically complex and life limiting illness would benefit from SPC services being provided to their children and/or grandchildren to help them process and cope with the parent or grandparent's serious illness.

Child life specialists (CLS) are an important part of the SPC team because they can provide services that benefit both adults and children. CLSs offer psychosocial support to pediatric patients and to the children of seriously ill adult patients by helping improve a child's coping skills, aiding in the development of a holistic pain management and other symptom management strategies, and improving the overall patient experience.[41] Support provided to adults with a serious illness by CLSs are geared towards helping adults ensure that they feel empowered to provide guidance and support to the children they love in addition to assisting children when desired in a one on one tailored consult. CLSs do not provide pain management strategies or interventions to adults for their own discomfort.

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[39] Institute of Medicine (US). Committee on Palliative and End-of-Life Care for Children and Their Families, Board on Health Services Policy, Institute of Medicine. When Children Die: Improving Palliative and End-of-Life Care for Children and Their Families. Washington, DC: National Academies Press, 2003. https://pubmed.ncbi.nlm.nih.gov/25057608/

[40] 10 Patient Protection and Affordable Care Act, 42 USC § 18001 (2010). Patient Protection and Affordable Care Act. https://www.supremecourt.gov/qp/19-00454qp.pdf

[41] Heckler-Medina., GA. (2006). The importance of child life and pain management during vascular access procedures in pediatrics. Journal of the Association for Vascular Access. 2006;11(3):144–151. DOI: 10.2309/JAVA.11-3-10

Despite the benefits of CLS interventions, there is currently a lack of adequate funding for these providers. Funding for CLS positions is typically provided through multiple sources, including through hospital operational funds, grants, or by other philanthropic means that only provide short-term funding opportunities.

Recommendation

All Texas SPC interdisciplinary teams should include educated and trained SPC child life specialists as essential members of the team for both adult and pediatric patients, when deemed necessary. The Texas Legislature should also request HHSC to develop a pilot program to assess potential cost savings that may result from allocating state funds to help establish and maintain CLS positions in clinical and community-based settings.

Discussion

The Child Life Specialist profession began in the early 1900's in an effort to provide cost-effective improvements to the patient experience for both adults and children. CLS interventions align with today's value-based healthcare system expectations that hospitals, clinics, and other providers offer high quality care at sustainable costs. CLSs deliver services in inpatient units, outpatient clinics, and at homes of terminally ill children, but are mostly found in the hospital setting. CLSs are more commonly found in pediatric hospitals than adult hospitals and the extent to which they are part of the SPC team often varies. The minimum educational requirements for these specialists include a bachelor's degree from an Association of Child Life Professionals-endorsed child life academic program or specific coursework in child development topics.[42] Certification is also highly recommended for these providers, and they can obtain the Certified Child Life Specialist designation through an exam-based certification process along with meeting certain clinical and academic requirements.[43] There are also continuing education requirements that must be completed every five years to maintain certification.[44]

CLSs facilitate interventions to children that include therapeutic play, expressive modalities, memory making, normalized play, legacy building for end of life, coping skill development, pain management strategies, and procedural preparation to help them cope with otherwise overwhelming circumstances. Studies have shown that

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[42] Eligibility requirements. (n.d.). Association of child life professionals. https://www.childlife.org/certification/becoming-certified/requirements-after-2019
[43] Becoming certified. (n.d.). Association of child life professionals. https://www.childlife.org/certification/becoming-certified
[44]Recertifications options, dates, and fees (n.d.). Association of child life professionals. https://www.childlife.org/certification/recertification/recertification-options-dates-and-fees

child life interventions have been shown to provide cost savings benefits, including reduced sedation-related costs, and increased compliance during procedures, resulting in procedure completion.[45,46] Examples of how CLS interventions benefit the care of pediatric patients and provide cost-savings include:

- Improving pain management with decreased use of pain medications for children receiving treatments.[47]
- Eliminating the need for sedation during MRIs, lumbar punctures, CT scans, pin removals, and providing support for various other procedures.
- Avoiding anesthesia during extensive dental work treatments.[48]

CLS interventions such as bereavement support may also help mitigate unhealthy and risky behaviors, especially for children losing a parent, sibling, or other family member during their childhood. Such behaviors may include criminal behavior, promiscuity, dropping out of school, eating disorders, substance use disorders, and suicide attempts.[49] Additionally, CLSs support pediatric patients with terminal conditions as they process their imminent death.

CLSs can also aid adults during difficult medical circumstances by empowering them with knowledge and skills to increase their confidence in supporting the children they love, whether the child is a pediatric patient, or their sibling, or the adult has a serious illness that psychosocially impacts the child. A survey of mothers diagnosed with cancer reported that few were offered help with talking to their children about their illness and would have liked help with these discussions.[50] CLSs can offer education about diagnosis and treatment for pediatric patients and help explain an adult's diagnosis and treatment to children.

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[45] Scott MT, Todd KE, Oakley H, et al. (2016).Reducing anesthesia and health care cost through utilization of child life specialists in pediatric radiation oncology. Int J Radiat Oncol Biol Phys. 2016;96(2):401–405. DOI: 10.1016/j.ijrobp.2016.06.001.

[46] Khan., J.J, Donnelly., L.F, Koch., B.L, Curtwright., L. A, Dickerson., J.M, Hardin., J.L. A program to decrease the need for pediatric sedation for CT and MRI. Appl Radiol. 2007;36(4):30–33 DOI:10.37549/AR1505

[47] Jennifer., Weiner, Rosie., Zeno, Susan., E. Thrane, Kristine., K. Browning. (2020). Decreasing Opioid Use in Pediatric Lower Extremity Trauma: A Quality Improvement Project. https://www.sciencedirect.com/science/article/pii/S0891524520301292

[48] Hinze., T. McDonald., C. Kerins., C. A. McWhorter., A. G. (2020). Child Life Interventions for Pediatric Dental Patients: A Pilot Study. *Pediatric dentistry*, *42*(4), 252–255. https://pubmed.ncbi.nlm.nih.gov/32847664/

[49] Burns., M. Griese., B. King., S. Talmi., A. (2020). Childhood bereavement: Understanding prevalence and related adversity in the United States. *American Journal of Orthopsychiatry*, *90*(4), 391. https://psycnet.apa.org/fulltext/2020-06195-001.html

[50] Barnes., J. Kroll., L. Burke., O. Lee., J. Jones., A. Stein., A. (2000). Qualitative interview study of communication between parents and children about maternal breast cancer. BMJ (Clinical research ed.), 321(7259), 479–482. https://doi.org/10.1136/bmj.321.7259.479

Funding for CLS positions in the clinical setting is typically obtained from a variety of sources, including through a hospital's own operational funds, grants or by other philanthropic means that only provide short-term funding. Grant funding that is obtained commonly comes from local or regional organizations that support programming for children or grief/bereavement. Children's Miracle Network is an organization that helps fund CLS positions, but funding is limited to pediatric facilities. For CLSs working in non-traditional settings (adult hospital facilities, hospice organizations, schools, etc.) funding sources are primarily grant-based.

Due to a lack of funding for CLS positions in the clinical and community-based settings, the Texas Legislature should request that HHSC develop a pilot program to assess potential cost savings that may result from allocating state funds to help establish and maintain CLS positions in clinical and community-based settings. One way that this could be done would be for the state to provide funding for a pilot program utilizing a step-down model of funding to help launch child life programs in Texas hospitals. This would provide initial full funding for the CLS position and additional partial support over the course of a few years to help the hospital transition into a hospital-sustained financial model. This method has been previously used with success by a hospital who pursued the step-down model of funding over a three-year period to establish and maintain a child life specialist program.[51]

Policy Issue: Promote Provider and Health Care Professional Continuing Education Opportunities

SPC is its own health care specialty composed of multiple members of the team who contribute to the care of high risk and vulnerable patients who have serious and often limiting ill patients. Educating the diverse array of interdisciplinary team members can be a challenge. Each member must be specialty trained according to their specific discipline and role requirements in SPC. Certain disciplines do not have specific SPC training requirements and/or lack adequate access to continuing education training in their area of the state. Therefore, providing evidenced-based educational information virtually via online webinar trainings and through website pages would expand access to provider and health care professional SPC specialty continuing education training. Unfortunately, there is currently a lack of adequate virtual training and website resources that have certified continuing education credits for the diverse IDT members on hospice care and SPC related topics.

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[51] Gee., J. et al. (2016). Meeting the needs of the patient population: reevaluating the hospital donation process. Child life council bulletin. https://www.childlife.org/docs/default-source/Publications/Bulletin/vol-34-number-4-fall-2016.pdf

Recommendation

Texas should increase access to continuing education opportunities in SPC and hospice related topics for the entire interdisciplinary SPC team which may include physicians, APRNs, PAs, nurses, social workers, chaplains, child life specialists and pharmacists. The Texas legislature should appropriate funding to support academic health care facilities and other programs to provide free and low-cost continuing education, training, and certification specialty preparation for hospice and SPC related topics. Providers and health care professionals whose professions have a certificate and/or board certification in SPC and/or hospice care should pursue these educational opportunities ensure gold standard of high quality and evidenced-based specialty care.

Discussion

Several states are currently implementing continuing medical education requirements to build provider capacity in SPC. The medical boards and licensing authorities of California, Massachusetts, New Jersey, Oregon, Rhode Island, and Vermont require continuing medical education in end-of-life care, palliative care and/or pain management. Vermont also requires physicians to demonstrate competence in identifying and referring patients to hospice, palliative care, and pain management services by completing at least one hour of qualifying CME credits on these topics, as required by its Medical Practice Act.[52] Georgia's physicians who work in pain management clinics must demonstrate coursework in palliative care.[53]

APRNs currently have hospice and palliative care national board certification through the Hospice and Palliative Care Nurses Association/Hospice and Palliative Care Credentialing Center. This is in addition to their other primary national boards under the American Association of Nurse Practitioners (AANP) or American Nurses Credentialing Center (ANCC) and their Texas Board of Nursing state licensure. Texas APRNs are not mandated to be board certified in SPC and hospice care but have continued to show high growth in the ACHPN board credentialing since the

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[52] Vermont Department of Health Board of Medical Practice. (n.d.). Rule of the Board of Medical Practice Section I. General Provisions effective October 15, 2017. http://www.healthvermont.gov/sites/default/files/documents/pdf/BMP_Board%20Rules%20Effective%202017.pdf

[53]GA-GAC- Department 360. Rules of Georgia composite Medical Board. (n.d.). Chapter 360-8 Pain Management Clinics. http://rules.sos.state.ga.us/gac/360-8?urlRedirected=yes&data=admin &lookingfor=360-8.

initial tracking by HHSC on the last PCIAC report to the 87th legislative session.[54] The report also showed a 152% growth seen since the inception of the PCIAC in the 84th legislative session.

Physician assistants are not certified by the State of Texas but can be certified by the National Commission on Certification of PAs. Once certification is obtained, PAs can apply for Texas Medical Board licensure and are able to work in all specialties. Currently, there is no specific board certification in hospice and palliative care for PAs. However, the NCCPA is developing a board specialty certification program in HPM that will become available in the spring of 2023. Current requirements and information regarding this specialty board exam for PAs can be found on the NCCPA website.[55]

Since 2017, the PCIAC has worked with the state's Palliative Care Information and Education program to develop and provide SPC -related continuing education opportunities and resources to providers and health care professionals across the state through hosting annual continuing education (CE) events. These events award CE credits to interdisciplinary professionals on current topics in SPC and include ethics credits opportunities. To date, these events have awarded about 1500 CE hours to interdisciplinary professionals. These live webinar events are typically held in November and are free to the public. Please email Palliative_Care@hhsc.state.tx.us if you are interested in receiving notifications about upcoming continuing education events. The PCIAC also provides updated

[54] Health and Human Services Commission (2020). Texas Palliative Care Interdisciplinary Advisory Council Recommendations to the 87th Texas Legislature. https://www.hhs.texas.gov/sites/default/files/documents/laws-regulations/reports-presentations/2020/txpciac-recs-86th-leg-oct-2020.pdf

[55] NCCPA (2022). Specialty certificates. https://www.nccpa.net/specialty-certificates/#palliative-medicine-hospice

resources on SPC and hospice care to the public and to all health care professionals and providers via the Council website pages.[56,57,58,59,60]

Important topics that health care professionals should pursue CE credit for include specialty SPC pain management, nutritional support, medication management in addition to non-pain symptom management, end of life care, mental and emotional care, psychosocial care, spiritual care, complex communication in serious and end of life care and advance care planning.

Other national palliative care organizations that provide web-based resources and training include CAPC, which provides its members with free online continuing education training with credits available for physicians, APRNs, nurses and social workers.[5] Additional national SPC website resources which provide information and educational resources for both patients and health care professionals include CAPC, the National Hospice and Palliative Care Organization (NHPCO), Hospice and Palliative Nurses Association, and the American Academy of Hospice and Palliative Medicine.

While SPC continuing education is needed for health care professionals and consumers, education to academia at the community college, undergraduate, graduate and post doctorate levels are vital in keeping up with working functional knowledge across the IDT roles and setting on primary and specialty SPC and hospice care topics. This will help to ease the lack of awareness and angst in SPC and hospice care topics in addition to providing awareness and confidence when encountering the high risk and vulnerable SPC patient population.

Policy Issue: Establishment of a SPC Awareness Day

When providing quality care to patients with serious and life limiting illness, curative attempts at treatment are often not enough to meet a patient's needs. SPC

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[56] Texas Health and Human Services. Palliative care. https://www.hhs.texas.gov/services/health/palliative-care

[57] Texas Health and Human Services. Hospice care. https://www.hhs.texas.gov/services/health/palliative-care/hospice-care

[58] Texas Health and Human Services. Supportive Palliative Care. https://www.hhs.texas.gov/services/health/palliative-care/supportive-palliative-care

[59] Texas Health and Human Services. Pediatric palliative care. https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers/pediatric-palliative-care

[60] Texas Health and Human Services. Palliative care for providers. https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers

is delivered to address the physical, emotional, and spiritual needs of individuals and their families with serious and often life limiting illnesses. According to a 2019 report by the National Academy for State Health Policy, less than 5% of patients with serious illness who could benefit from SPC actually receive it.[61]

SPC is patient-centered, family-focused care that provides a patient and family with decreased symptom burden caused from serious and often life limiting illness they suffer from like pain, stress, and psychosocial distress. SPC is provided by an interdisciplinary team offering an additional layer of support to the patient and family. Unlike hospice care, which is often limited to those near the end of life, SPC can be delivered alongside attempts at disease modification and/or curative treatment at any stage of a serious illness. If the gold standard of SPC care delivery is followed appropriately, SPC is provided in a holistic and interdisciplinary team approach, which helps to balance comfort and function of the patient while supporting the caregiver team of the patient. SPC is provided at any stage of a serious and/or life-limiting illness. SPC is consistently shown to improve health outcomes and quality of life, while avoiding undesired and often non-beneficial care that then leads to decreased utilization costs for high-need and costly interventions.[62] A study of Medicaid enrollees diagnosed with serious illness and/or a history of hospitalization found that palliative care contributed to an average savings of almost $7,000 per person when compared to patients who did not receive palliative care.[63] Defining SPC is the first goal in expanding public and health care professional awareness and decreasing confusion.

A SPC awareness day in Texas should be established to spur the development of annual events and activities to raise awareness, education, and funds to support the advancement of SPC statewide.

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[61] Sanborn, L., Purington, K. (2019). Palliative-Care-A-Primer-for-State-Policymakers.pdf. A publication of the national academy for state health policy.
https://www.nashp.org/palliative-care-a-primer-for-state-policymakers/
[62] Samantha, Smith; et al. Evidence on the cost and cost-effectiveness of palliative care: A literature review. Palliative Medicine 28, no. 2 (July 2013): 130-150. doi: 10.1177/0269216313493466
[63] Morrison, R. Sean., et al. (2011). Palliative Care Consultation Teams Cut Hospital Costs For Medicaid Beneficiaries. Health Affairs 30, no. 3 (Mar. 2011). doi: 10.1377/hlthaff.2010.0929. PMID: 21383364.

Recommendation

Texas should adopt October 10th as Supportive Palliative Care Awareness Day to raise awareness about supportive palliative care optimizing the quality of life and improvement of care for seriously ill patients and their families.

Discussion

Awareness of the benefits of SPC in Texas is on the rise, in part thanks to the efforts of this Council, which provides free annual public continuing education events on SPC and hospice care related topics as well as updated resources to consumers and clinicians via the Council website pages.[64,65,66,67,68] On SPC Awareness Day or at least annually, healthcare providers should visit the HHSC supportive palliative care website pages to review up to date information on SPC and HC. They should direct patients to these pages for additional resources about the role and benefits of SPC from HC. Additional national SPC website resources which provide information and educational resources for both patients and providers include CAPC, NHPCO, World Hospice and Palliative Care Alliance (WHPCA) and others.

Texas has an opportunity in joining and recognizing a global effort for Supportive Palliative Care Awareness Day in unified voice. SPC Awareness Day on October 10th annually can provide a spotlight for consumers and clinicians across Texas in their resolve and commitment for ensuring all Texans have access to high quality and affordable evidenced based SPC across 254 counties.

Substantial gaps in access to SPC still persist. Some Texas communities, such as the Rio Grande Valley, El Paso, and rural areas are particularly disadvantaged regarding palliative care infrastructure. An SPC Awareness Day could help bring communities together in awareness, breaking the stigma and myths that abound in addition to bridging the gap for innovative solutions, partnerships and collaboration across the settings and health care professional roles and disciplines.

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[64] Palliative Care. https://www.hhs.texas.gov/services/health/palliative-care
[65] Hospice Care. https://www.hhs.texas.gov/services/health/palliative-care/hospice-care
[66] Supportive Palliative Care https://www.hhs.texas.gov/services/health/palliative-care/supportive-palliative-care
[67] Palliative Care for Providers https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers
[68] Pediatric Palliative Care https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers/pediatric-palliative-care

Educating health care professionals and consumers on the importance of having at minimum annual conversations regarding their expected health care and disease trajectory is one of the first steps to ensuring patient centered goals of care. Having open and ongoing conversations between the health care professionals, patients, families and caregivers help in decreasing angst and fear of the unknown and decreases burdens on all parties in clear last known wishes and goals of the patient prior to losing medical capacity for decision making. SPC Awareness Day can also highlight the need and remind all Texans on the vital importance to ensuring their Advanced Care Planning is not only discussed but also verifying the current elections are still desired and that all Texas specific Advanced Care Planning documents are all legally completed, copied and disseminated to their primary caregivers, family, health care facilities and health care providers. This can aid Texans in decreasing the risk fractured care and unknown ACP decisions.

SPC Awareness Day in Texas can bring other opportunities for SPC needs and topics for clinicians and consumers to be discussed. Additionally, incorporating an SPC Awareness Day in Texas would come at no cost to the state. This special day will help in efforts to acknowledge the high risk and vulnerable SPC patients, seek to improve the quality of life in symptom burden relief in addition to decreasing dollars in cents for Texans who clearly have opportunity for early SPC and support those specialty SPC health care professionals who care for all those in need.

Policy Issue: Expanding the Medicaid Hospice Benefit into the Prenatal Period to Improve Care for Children with a Terminal or Life-Limiting Illness

There is no payment model in Texas to support the provision of palliative care[69] to pregnant women when their fetus is diagnosed with a terminal or life-limiting illness.[70] Currently, healthcare professionals provide these services with minimal or

[69] Texas Health and Human Services describes palliative care as "patient-centered and family-focused, provided by a team of palliative care doctors, nurses, social workers and others who work together with a patient's other doctors to provide an extra layer of support." It also divides palliative care into two subtypes: supportive palliative care and hospice. This document will utilize these terms in the same manner. https://www.hhs.texas.gov/services/health/palliative-care

[70] The use of the "terminal illness" in this document aligns with the CMS definition of "a medical condition likely to result in death within six months or less if the illness runs its normal course"; in the context of a prenatally diagnosed medical condition, this is adjusted to "a medical condition likely to result in death prior to, or within six months of, a patient's birth if the illness runs its normal course."

no reimbursement because compassionate care is needed for these children and their families in the community.

A Family's Journey and the Importance of Perinatal Palliative Care

While receiving obstetrical care in her community, a woman elects to have a non-invasive prenatal test to screen for common fetal aneuploidies. When she returns for a follow-up visit one week later, she learns that the fetus is "high-risk for trisomy 18". The obstetrician spends time comforting the patient and answers questions regarding the diagnosis of trisomy 18. She offers a referral to the nearby fetal center for further evaluation and support, and the patient accepts.

During her initial visit to the fetal center, the patient receives a level two ultrasound, and the findings are consistent with trisomy 18 with an associated diagnosis of a ventricular septal defect. With the patient's permission, a referral is made to a SPC team. On her follow-up visit to the fetal center, a nurse and physician from the SPC team meet with the family, introduce the concept of palliative care, and provide a safe and quiet presence to process feelings about the diagnosis. A plan is made for the SPC team to call later in the week to check on the patient and discuss how their team might best support her and her family moving forward.

Throughout the rest of the pregnancy, the SPC team attends the patient's consultations with other specialists. They also provide phone calls and home visits to help the family emotionally process information, make decisions about treatment, discuss news about the pregnancy with their other children, and participate in memory-making and legacy-building activities like heartbeat recordings.

Prior to delivery, the team also works with the family, the delivering OB, and a neonatologist to create an advance care planning document, often referred to as a "birth plan". This document provides a summary of the family's desired medical interventions for their child, as well as information about who the family wants in the delivery room, a request for photos to be taken, and contact information for the SPC team. At the time of delivery, the SPC team provides a supportive presence and facilitates the details of the birth plan.

"Samuel" is born and experiences some initial trouble breathing. Because the family has decided they don't want to be separated from Samuel during the short time they have together, he stays in the room with his family instead of transferring to the neonatal intensive care unit. He begins to stabilize and is able to take a small amount of milk. Thrilled, the family asks that they be discharged thirty-six hours later, so that Samuel may experience being home. The SPC team helps facilitate

enrollment in a hospice program; three weeks later, Samuel dies peacefully at home, surrounded by his mom, dad, and two older sisters.

Recommendation

Every child and their family deserve individualized, comprehensive, and compassionate care. With an estimated 50% increase in the number of Texas children being born with a terminal or life-limiting illness, the PCIAC strongly recommends the creation of policy and funding initiatives that will increase access to pediatric palliative care, including prenatal services. [71,72,73,74,75] Recommended initiatives include the following:

1. The Texas Health and Human Services Commission (HHSC), working with the Center for Medicare and Medicaid Services and members of the Pediatric Subcommittee of the PCIAC should make Medicaid State Plan amendments and/or Medicaid waiver requests to:

    a. Expand eligibility for the Medicaid hospice benefit to include prenatal services for pregnant mothers with a child that has been diagnosed with a terminal or life-limiting illness; and
    b. Create special reimbursement classes for the Medicaid hospice benefit that can be used in research and demonstration projects intended to improve access to hospice and supportive palliative care services.

With funding appropriated by the Texas legislature, a state-wide pediatric palliative care network should be created based on the Texas Child Psychiatry Access Network (CPAN). The network will improve access to pediatric palliative care in rural and understaffed areas by providing provider-to-provider consultations related to specific patients, educational programs, and support to adult-focused programs

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[71] Schechtman, K., 2002. Decision-making for termination of pregnancies with fetal anomalies: Analysis of 53,000 pregnancies. *Obstetrics & Gynecology*, 99(2), pp.216–222. https://pubmed.ncbi.nlm.nih.gov/11814500/

[72] Bourke, J. et al., 2005. The effect of terminations of pregnancy for fetal abnormalities on trends in mortality to one year of age in Western Australia. *Paediatric and Perinatal Epidemiology*, 19(4), pp.284–293. https://pubmed.ncbi.nlm.nih.gov/15958151/

[73] Western Australia Statistics – births, deaths, and marriages registered. https://www.wa.gov.au/organisation/department-of-justice/the-registry-of-births-deaths-and-marriages/statistics-births-deaths-and-marriages-registered

[74] Texas Health Data, Live Births in Texas, 2005-2019. https://healthdata.dshs.texas.gov/dashboard/births-and-deaths/live-births

[75] Texas Health Data, Deaths (2006-2019). https://healthdata.dshs.texas.gov/dashboard/births-and-deaths/deaths-2006-2019

providing supportive palliative care and hospice services to prenatal and pediatric patients. HHSC should work with key stakeholders to create specific guidance for hospice programs as they fully implement federal concurrent care regulations for pediatric patients, including the enrollment of patients receiving medical care in an acute care hospital if they meet the prognosis criteria.

Discussion

There is published data demonstrating that pediatric palliative care services reduce overall healthcare expenditures, offsetting the expenditures of expanding the hospice benefit. This was achieved not by rationing or denying healthcare, but instead by improving effective communication and decision-making between families and healthcare providers. Also, for many patients their location of care prior to death was shifted from the inpatient setting to home, further reducing cost of care while meeting the goals of the patient and family regarding where they spent their last days or weeks together.[76,77,78]

If approved by the Centers for Medicare & Medicaid Services (CMS) via a waiver or state plan amendment, the increase in the state Medicaid spending required to expand the Texas Medicaid hospice benefit and/or test new payment models would be partially supported by federal matching funds (FMAP). Based on the current federal share of funding for Texas Medicaid programs, excluding the additional 6.2% of additional funding during the public health emergency, the state of Texas would fund 40% of the additional cost as the non-federal share.[79]

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[76] Gans, D. et al., 2016. Cost analysis and policy implications of a Pediatric Palliative Care Program. Journal of Pain and Symptom Management, 52(3), pp.329–335. https://pubmed.ncbi.nlm.nih.gov/27233140/

[77] Lysecki, D.L. et al., 2022. Children's health care utilization and cost in the last year of life: A cohort comparison with and without regional specialist pediatric palliative care. *Journal of Palliative Medicine*, 25(7), pp.1031–1040. https://pubmed.ncbi.nlm.nih.gov/34981956/

[78] Fraser, L.K. et al., 2013. Does referral to specialist paediatric palliative care services reduce hospital admissions in oncology patients at the end of life? *British Journal of Cancer*, 108(6), pp.1273–1279. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3619259/

[79] The citations listed throughout this recommendation do not reflect the personal or institutional views of any member of the council but given the limited data on the topic, they are included to provide some data for the recommendation. Any commentary or conclusions of the authors in these citations does not reflect the views of any contributor or member of this council.

8. 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 supportive 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.

This fourth legislative report is a result of the Council's efforts to continue to provide meaningful, innovative recommendations while mindful of appropriate fiscal stewardship during appropriation considerations in these ever-evolving contexts. To build on this momentum, the Council convened three times during 2022 in Austin as well as virtually to develop the findings and recommendations published in this 2022 report. The meetings occurred in full public view and in partnership with the many stakeholders committed to improving supportive palliative care services in Texas. The Council's recommendations support the Legislature's original belief that significant advancements in supportive palliative care are possible in Texas when teams collaborate for good of the patient and place patients first. Expert collaboration of interdisciplinary supportive palliative care specialist are improving the quality of life of seriously ill patients, their families and care teams while improving the fiscal stewardship of health care utilization by placing the patients goals of care first when determining the focus of health care directed therapies.

The Council hopes its fourth report can serve as a renewed catalyst for sustained quality improvement efforts. Council reaffirms the commitment to further advance SPC in Texas and the nation by providing evidenced based, compassionate, and high-quality specialty supportive palliative care to at risk and vulnerable Texans suffering from a serious and/or life-threatening illness, which is provided at any age and at any stage of serious illness.

List of Acronyms

Acronym	Full Name
ACA	Affordable Care Act
ACHPN	Advanced Certified Hospice and Palliative Nurses
ACP	Advance Care Planning
AD	Advanced Directive
AHA	American Hospital Association
APM	Alternative Payment Model
APRN	Advanced Practice Registered Nurse
BRFSS	Behavioral Risk Factor Surveillance System
CAPC	Center to Advance Palliative Care
CE	Continuing Education
CLS	Child Life Specialist
CME	Continuing Medical Education
CMS	Centers for Medicare & Medicaid Services
CPAN	Child Psychiatry Access Network
CPT	Current Procedural Terminology
COPD	Chronic Obstructive Pulmonary Disease
DNI	Do Not Intubate
DNR	Do Not Resuscitate
DPOA	Durable Power Of Attorney
DSRIP	Delivery System Reform Incentive Payment
ED	Emergency Department
EOL	End Of Life
FMAP	Federal Matching Funds
HB	House Bill
HC	Hospice Care
HCPCS	Healthcare Common Procedure Coding System
HEDIS	Healthcare Effectiveness Data and Information Set
HHSC	Health and Human Service Commission

Acronym	Full Name
HPCC	Hospice and Palliative Credentialing Center
HPM	Hospice and Palliative Medicine
IDT	Interdisciplinary Team
IP	Inpatient Hospital
MCO	Managed Care Organization
MMP	Medicare-Medicaid Plan
MPOA	Medical Power of Attorney
NCCPA	National Commission on Certification of Physician Assistants
NHPCO	National Hospice and Palliative Care Organization
NQF	National Quality Forum
PA	Physician Assistant
PCIAC	Palliative Care Interdisciplinary Advisory Council
PHR	Public Health Region
OB	Obstetrics or Obstetrician
OOHDNR	Out of Hospital Do Not Resuscitate
SB	Senate Bill
SPC	Supportive Palliative Care
WHPCA	World Hospice and Palliative Care Alliance

Appendix A.

Table 6: Behavioral Risk Factor Surveillance System, 2018 Medical Preferences, Adults 65+

Question: If a terminal illness or serious accident left you unable to communicate, would a family member, friend, doctor, or other person know your medical or health care treatment preferences?

Demographics	Sample Size	%	95% CI	%	95% CI
Sex: Male	1,242	79.4	(73.1 - 84.6)	20.6	(15.4 - 26.9)
Sex: Female	1,992	85.1	(79.1 - 89.5)	14.9	(10.5 - 20.9)
Race/Ethnicity: White, Non-Hispanic	2,434	88.2	(84.7 - 90.9)	11.8	(9.1 - 15.3)
Race/Ethnicity: Black, Non-Hispanic	228	66.3	(45.4 - 82.3)	33.7	(17.7 - 54.6)
Race/Ethnicity: Hispanic	410	75.4	(64.3 - 83.9)	24.6	(16.1 - 35.7)
Race/Ethnicity: Other/Multiracial, Non-Hispanic	109	67.6	(40.1 - 86.7)	R	(. - .)
Education: Less than high school	360	72.5	(60.2 - 82.1)	27.5	(17.9 - 39.8)
Education: High school graduate and some college	1,654	84.6	(79.0 - 88.9)	15.4	(11.1 - 21.0)
Education: College graduate	1,230	89.0	(84.7 - 92.3)	11.0	(7.7 - 15.3)
Income: <$25,000	742	80.5	(72.0 - 86.9)	19.5	(13.1 - 28.0)
Income: $25,000 to <$50,000	683	83.5	(74.9 - 89.6)	16.5	(10.4 - 25.1)
Income: $50,000+	1,044	88.2	(83.1 - 91.9)	11.8	(8.1 - 16.9)
Marital Status: Married	1,586	83.6	(78.3 - 87.9)	16.4	(12.1 - 21.7)
Marital Status: Unmarried	1,649	82.1	(75.1 - 87.5)	17.9	(12.5 - 24.9)
Disability: Yes	1,508	79.0	(71.3 - 85.0)	21.0	(15.0 - 28.7)
Disability: No	1,706	86.1	(82.0 - 89.4)	13.9	(10.6 - 18.0)
Health Insurance: Yes	3,174	84.8	(80.8 - 88.1)	15.2	(11.9 - 19.2)
Health Insurance: No	66	41.7	(22.9 - 63.3)	58.3	(36.7 - 77.1)
Chronic Condition: Yes	3,022	83.0	(78.6 - 86.7)	17.0	(13.3 - 21.4)
Chronic Condition: No	229	79.4	(67.6 - 87.6)	20.6	(12.4 - 32.4)
Total	**3,252**	**82.8**	**(78.6 - 86.2)**	**17.2**	**(13.8 - 21.4)**

Note: N = Sample size less than 50, estimate not displayed. R = Relative Standard Error greater than 30%, estimate unreliable and not displayed. All reported rates are weighted for Texas demographics and the probability of selection. Prepared by: Center for Health Statistics, Texas Department of State Health Services

Table 7: Texas Behavioral Risk Factor Surveillance System, 2018

Medical Preferences by Risk Factor, Adults 65+

Question: If a terminal illness or serious accident left you unable to communicate, would a family member, friend, doctor, or other person know your medical or health care treatment preferences?

Ever Diagnosed with Any Cancer?	Sample Size	% Yes	Yes 95% CI	% No	No 95% CI
Yes	1,044	86.4 %	(75.4 - 92.9)	R	(. - .)
No	2,179	81.4 %	(76.7 - 85.3)	18.6 %	(14.7 - 23.3)

Heart Disease?	Sample Size	% Yes	Yes 95% CI	% No	No 95% CI
Yes	603	80.2 %	(70.6 - 8733)	R	(. - .)
No	2,595	83.5 %	(78.7 - 87.4)	16.5 %	(12.6 - 21.3)

Cardiovascular Disease?	Sample Size	% Yes	Yes 95% CI	% No	No 95% CI
Yes	758	78.9 %	(69.9 - 85.8)	R	(. - .)
No	2,439	84.1 5	(79.2 - 88.1)	R	(. - .)

Diabetes?	Sample Size	% Yes	Yes 95% CI	% No	No 95% CI
Yes	824	83.8 %	(77.2 - 88.7)	R	(. - .)
No	2,420	82.3 %	(77.0 - 86.7)	R	(. - .)

Note: N = Sample size less than 50, estimate not displayed. R = Relative Standard Error greater than 30%, estimate unreliable and not displayed. Prepared by: Texas Health and Human Services Commission

Table 8: Texas Behavioral Risk Factor Surveillance System, 2018

Medical Preferences by Region, Adults 65+

Question: If a terminal illness or serious accident left you unable to communicate, would a family member, friend, doctor, or other person know your medical or health care treatment preferences?

Variable	Sample Size	% Yes	Yes 95% CI	% No	No 95% CI
Public Health Region – Texas: 1/2	296	90.7	(79.0 - 96.2)	N	(.-.)
Public Health Region – Texas: 3	631	88.9	(84.5 - 92.2)	R	(.-.)
Public Health Region – Texas: 4/5	379	73.5	(57.0 - 85.3)	R	(.-.)
Public Health Region – Texas: 6	389	83.3	(70.9 - 91.1)	N	(.-.)
Public Health Region – Texas: 7	841	77.3	(63.1 - 87.2)	R	(.-.)
Public Health Region – Texas: 8/11	421	82.7	(72.9 - 89.5)	R	(.-.)
Public Health Region – Texas 9/10	164	83.3	(69.9 - 91.4)	N	(.-.)
Border: Yes	316	80.1	(69.9 - 87.5)	R	(.-.)
Border: No	2,805	83.8	(79.6 - 87.3)	16.2	(12.7 - 20.4)
Metro Statistical Area: Yes	2,627	85.4	(81.54 - 88.7)	14.6	(11.3 - 18.6)
Metro Statistical Area: No	494	73.9	(61.7 - 83.2)	R	(.-.)
Total	**3,121**	**83.5**	**(79.7 - 86.8)**	**16.5**	**(13.2 - 20.3)**

Note: N = Sample size less than 50, estimate not displayed. R = Relative Standard Error greater than 30%, estimate unreliable and not displayed. Prepared by: Texas Health and Human Services Commission

Table 9: Texas Behavioral Risk Factor Surveillance System, 2018

Advance Directive, Adults 65+

Question: Do you have a written advance directive?

Demographics	Sample Size	% Yes	Yes 95% CI	% No	No 95% CI
Sex: Male	1,246	46.3	(39.8 - 52.9)	53.7	(47.1 - 60.2)
Sex: Female	1,998	54.8	(49.3 - 60.3)	45.2	(39.7 - 50.7)
Race/Ethnicity: White, Non-Hispanic	2,431	60.5	(55.6 - 65.1)	39.5	(34.9 - 44.4)
Race/Ethnicity: Black, Non-Hispanic	227	38.3	(22.3 - 57.2)	61.7	(42.8 - 77.7)
Race/Ethnicity: Hispanic	423	30.6	(22.9 - 39.5)	69.4	(60.5 - 77.1)
Race/Ethnicity: Other/Multiracial, Non-Hispanic	111	40.7	(22.3 - 62.1)	59.3	(37.9 - 77.7)
Education: Less than high school	374	30.2	(21.8 - 40.2)	69.8	(59.8 - 78.2)
Education: High school graduate and some college	1,656	54.1	(48.5 - 59.6)	45.9	(40.4 - 51.5)
Education: College graduate	1,223	67.5	(61.6 - 72.9)	32.5	(27.1 - 38.4)
Income: <$25,000	751	41.5	(33.0 - 50.5)	58.5	(49.5 - 67.0)
Income: $25,000 to <$50,000	683	50.0	(41.6 - 58.4)	50.0	(41.6 - 58.4)
Income: $50,000+	1,043	61.1	(53.6 - 68.2)	38.9	(31.8 - 46.4)
Marital Status: Married	1,592	49.0	(43.2 - 54.9)	51.0	(45.1 - 56.8)
Marital Status: Unmarried	1,650	54.4	(48.2 - 60.5)	45.6	(39.5 - 51.8)
Disability: Yes	1,516	47.2	(40.5 - 53.9)	52.8	(46.1 - 59.5)
Disability: No	1,705	55.7	(50.2 - 61.1)	44.3	(38.9 - 49.8)
Health Insurance: Yes	3,184	52.7	(48.3 - 57.0)	47.3	(43.0 - 51.7)
Health Insurance: No	69	R	(. - .)	74.1	(53.6 - 87.7)
Chronic Condition: Yes	3,031	51.7	(47.2 - 56.2)	48.3	(43.8 - 52.8)
Chronic Condition: No	229	48.2	(35.3 - 61.2)	51.8	(38.8 - 64.7)
Total	**3,261**	**51.4**	**(47.1 - 55.7)**	**48.6**	**(44.3 - 52.9)**

Note: N = Sample size less than 50, estimate not displayed. R = Relative Standard Error greater than 30%, estimate unreliable and not displayed. Prepared by: Center for Health Statistics, Texas Department of State Health Services

Table 10: Texas Behavioral Risk Factor Surveillance System, 2018

Advance Directive by Risk Factor, Adults 65+

Question: Do you have a written advance directive?

Ever Diagnosed with Any Cancer?	Sample Size	% Yes	Yes 95% CI	% No	No 95% CI
Yes	1,035	57.3	(49.2 - 65.0)	42.7	(35.0 - 50.8)
No	2,199	49.1	(44.1 - 54.2)	50.1	(45.8 - 55.9)

Heart Disease?	Sample Size	% Yes	Yes 95% CI	% No	No 95% CI
Yes	602	59.1	(49.7 - 67.8)	40.9	(32.2 - 50.3)
No	2,605	50.7	(45.8 - 55.5)	49.3	(44.5 - 54.2)

Cardiovascular Disease?	Sample Size	% Yes	Yes 95% CI	% No	No 95% CI
Yes	755	58.8	(50.5 - 66.7)	41.2	(33.3 - 49.5)
No	2,450	50.4	(45.4 - 55.5)	49.6	(44.5 - 54.6)

Diabetes?	Sample Size	% Yes	Yes 95% CI	% No	No 95% CI
Yes	830	45.2	(37.2 - 53.4)	54.8	(46.6 - 62.8
No	2,423	54.0	(49.0 - 59.0)	46.0	(41.1 - 51.0)

Prepared by: Texas Health and Human Services Commission

Table 11: Texas Behavioral Risk Factor Surveillance System, 2018

Advance Directive by Region, Adults 65+

Question: Do you have a written advance directive?

Variable	Sample Size	% Yes	Yes 95% CI	% No	No 95% CI
Public Health Region – Texas: 1/2	298	62.7	(45.9 - 77.0)	R	(.-.)
Public Health Region – Texas: 3	630	54.9	(47.5 - 62.1)	45.1	(37.9 - 52.5)
Public Health Region – Texas: 4/5	376	R	(.-.)	60.2	(45.8 - 73.1)
Public Health Region – Texas: 6	388	51.5	(40.0 - 62.8)	48.5	(37.2 - 60.0)
Public Health Region – Texas: 7	841	57.2	(46.5 - 67.3)	42.8	(32.7 - 53.5)
Public Health Region – Texas: 8/11	426	44.8	(35.1 - 54.9)	55.2	(45.1 - 64.9)
Public Health Region – Texas: 9/10	169	R	(.-.)	58.4	(42.5 - 72.7)
Border: Yes	328	R	(.-.)	69.9	(57.6 - 79.8)
Border: No	2,800	53.2	(48.7 - 57.7)	46.8	(42.3 - 51.3)
Metro Statistical Area: Yes	2,638	51.3	(46.7 - 56.0)	48.7	(44.0 - 53.3)
Metro Statistical Area: No	490	50.1	(38.3 - 61.9)	49.9	(38.1 - 61.7)
Total	**3,128**	**51.1**	**(46.8 - 55.5)**	**48.9**	**(44.5 - 53.2)**

Note: N = Sample size less than 50, estimate not displayed. R = Relative Standard Error greater than 30%, estimate unreliable and not displayed. Prepared by: Texas Health and Human Services Commission