

Draft PCIAC 2022 Report Recommendations

Policy Issue: Child Life Specialists are Essential Members of the Supportive Palliative Care Team

Each year, more than 500,000 children in the United States cope with life-threatening conditions.¹ 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.² 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 supportive palliative care (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

¹ 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/>

² 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>

overall patient experience.³ 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.

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.⁴ Certification is also highly recommended for these providers, and they can obtain the Certified Child Life Specialist (CCLS) designation through an exam-based certification process along with meeting certain clinical and

³ 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

⁴ Eligibility requirements. (n.d.). [Association of child life professionals.](https://www.childlife.org/certification/becoming-certified/requirements-after-2019) <https://www.childlife.org/certification/becoming-certified/requirements-after-2019>

academic requirements.⁵ There are also continuing education requirements that must be completed every five years to maintain certification.⁶

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 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.^{7,8} 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.⁹
- 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.¹⁰

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

⁵ Becoming certified. (n.d.). [Association of child life professionals](https://www.childlife.org/certification/becoming-certified).

<https://www.childlife.org/certification/becoming-certified>

⁶Recertifications options, dates, and fees (n.d.). [Association of child life professionals](https://www.childlife.org/certification/recertification/recertification-options-dates-and-fees).

<https://www.childlife.org/certification/recertification/recertification-options-dates-and-fees>

⁷ 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.

⁸ 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

⁹ 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>

¹⁰ 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/>

suicide attempts.¹¹ 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.¹² CLSs can offer education about diagnosis and treatment for pediatric patients and help explain an adult's diagnosis and treatment to children.

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.¹³

¹¹ Burns., M. Griese., B. King., S. Talmi., A. (2020). [Childhood bereavement: Understanding prevalence and related adversity in the United States](https://psycnet.apa.org/fulltext/2020-06195-001.html). *American Journal of Orthopsychiatry*, 90(4), 391. <https://psycnet.apa.org/fulltext/2020-06195-001.html>

¹² 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](https://doi.org/10.1136/bmj.321.7259.479). *BMJ* (Clinical research ed.), 321(7259), 479–482. <https://doi.org/10.1136/bmj.321.7259.479>

¹³ Gee., J. et al. (2016). [Meeting the needs of the patient population: reevaluating the hospital donation process](https://www.childlife.org/docs/default-source/Publications/Bulletin/vol-34-number-4-fall-2016.pdf). *Child life council bulletin*. <https://www.childlife.org/docs/default-source/Publications/Bulletin/vol-34-number-4-fall-2016.pdf>

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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.^{14,15,16} 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 physician, advanced practice provider [advanced practice registered nurse (APRN) or physician assistant (PA)] and/or 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

¹⁴NQF: 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) https://www.qualityforum.org/projects/palliative_care_and_end-of-life_care.aspx

¹⁵ Palliative Care| Center to Advance Palliative Care (2020). [Serious illness quality alignment hub.](https://www.capc.org/toolkits/serious-illness-quality-alignment-hub/) <https://www.capc.org/toolkits/serious-illness-quality-alignment-hub/>

¹⁶[Quality Measurement and accountability for community-based serious illness care.](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) (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

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 would include encouraging that physicians and APRNs be board certified in hospice and palliative medicine or have a Hospice Medical Director certification 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.¹⁷

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

¹⁷[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). (2012).
https://www.qualityforum.org/Publications/2012/04/Palliative_Care_and_End-of-Life_Care%e2%80%94a_Consensus_Report.aspx

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 consistent patient and family-centered services, collaborates with partner organizations to facilitate timely and efficient internal and external care coordination, fosters a positive organizational culture of diversity, equality and inclusivity, strives for continuous evidenced-based quality 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 medicine 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.^{18,19} National organizations such as CAPC and the Texas Association of Home Care & Hospice also provide information and resources for home health agencies.^{20,21}

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

¹⁸ [Palliative care interdisciplinary advisory council.](https://www.hhs.texas.gov/about/leadership/advisory-committees/palliative-care-interdisciplinary-advisory-council)

<https://www.hhs.texas.gov/about/leadership/advisory-committees/palliative-care-interdisciplinary-advisory-council>

¹⁹ [Palliative care for providers.](https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers) <https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers>

²⁰ [Tools and training for clinicians: Palliative Care Programs.](https://www.capc.org/) Center to advance palliative care <https://www.capc.org/>

²¹ Regulations- TAHCH.org (n.d.). [Regulations.](https://tahch.org/regulatory/regulatoryinformation) <https://tahch.org/regulatory/regulatoryinformation>

care and hospice framework as well as its recommended performance measures.²² 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;
- 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.

²² 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).
https://www.qualityforum.org/projects/palliative_care_and_end-of-life_care.aspx

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

Completion of advance care planning (ACP) documents helps ensure that an individual's values and treatment wishes are known in an 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 patients 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) out of hospital do not resuscitate (OOHDNR), 4) in hospital do not resuscitate/intubate 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.²³ 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

²³ 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.

talked with someone about their wishes for medical treatment at the end of their lives.²⁴ 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.^{25,26} 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.²⁷

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

²⁴ Pew Research Center. (2013). [Views on End-of-Life Medical Treatments](http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/).

<http://www.pewforum.org/2013/11/21/views-on-end-of-life-medical-treatments/>

²⁵ Anne Wilkinson, Neil Wenger, and Lisa R. Shugarman [Literature Review on Advance Directives](http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.pdf). HHS Office of the Assistant Secretary for Planning and Evaluation, June 2007.

<http://aspe.hhs.gov/daltcp/reports/2007/advdirlr.pdf>

²⁶ Carr., D. (2011). [Racial differences in end-of-life planning: why don't Blacks and Latinos prepare for the inevitable?](https://doi.org/10.2190/OM.63.1.a). Omega (Westport). 2011;63(1):1-20. DOI: 10.2190/OM.63.1.a.

²⁷ Stinson, Matt, et al. (2019). [Compassionate Technology: Palliative Care Telemedicine in the Rural Hospital Setting \(QI741\)](https://doi.org/10.1016/j.jpainsymman.2018.12.250). Journal of Pain and Symptom Management 57.2 (2019): 478. DOI:10.1016/j.jpainsymman.2018.12.250

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 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.

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 vs. 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, Medical Power of Attorney (MPOA), durable power of attorney (DPOA), Texas Out of Hospital DNR (OOHDNR), 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.²⁸ 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.²⁹

²⁸ 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). <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.). <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/). <https://nursescarehub.com/education/>

²⁹ [Palliative care](https://www.hhs.texas.gov/services/health/palliative-care). <https://www.hhs.texas.gov/services/health/palliative-care>

Recommendations

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

Supportive palliative care (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.

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, 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.

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.³⁰ Georgia's physicians who work in pain management clinics must demonstrate coursework in palliative care.³¹

Advanced Practice Registered Nurses (APRNs) currently have hospice and palliative care national board certification through the Hospice and Palliative Care Nurses Association/Hospice and Palliative Care Credentialing Center. 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 initial tracking by HHSC on the last PCIAC report to the 87th legislative session.³² The report also showed a 107% 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 PA's (NCCPA). 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.³³

³⁰ Vermont Department of Health Board of Medical Practice. (n.d.). [Rule of the Board of Medical Practice Section I. General Provisions](http://www.healthvermont.gov/sites/default/files/documents/pdf/BMP_Board%20Rules%20Effective%202017.pdf) effective October 15, 2017. http://www.healthvermont.gov/sites/default/files/documents/pdf/BMP_Board%20Rules%20Effective%202017.pdf

³¹GA-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). <http://rules.sos.state.ga.us/gac/360-8?urlRedirected=yes&data=admin&lookingfor=360-8>.

³² 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/txpciacc-recs-86th-leg-oct-2020.pdf). <https://www.hhs.texas.gov/sites/default/files/documents/laws-regulations/reports-presentations/2020/txpciacc-recs-86th-leg-oct-2020.pdf>

³³ NCCPA (2022). [Specialty certificates](https://www.nccpa.net/specialty-certificates/#palliative-medicine-hospice). <https://www.nccpa.net/specialty-certificates/#palliative-medicine-hospice>

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 resources on SPC and hospice care to the public and to all health care professionals and providers via the Council website pages.^{34,35,36,37,38}

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 the Center to Advance Palliative Care (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 CE 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

³⁴ Texas Health and Human Services. (n.d.). [Palliative care.](https://www.hhs.texas.gov/services/health/palliative-care)

<https://www.hhs.texas.gov/services/health/palliative-care>

³⁵ Texas Health and Human Services. (n.d.).[Hospice care.](https://www.hhs.texas.gov/services/health/palliative-care/hospice-care)

<https://www.hhs.texas.gov/services/health/palliative-care/hospice-care>

³⁶ Texas Health and Human Services. (n.d.). [Supportive Palliative Care.](https://www.hhs.texas.gov/services/health/palliative-care/supportive-palliative-care)

<https://www.hhs.texas.gov/services/health/palliative-care/supportive-palliative-care>

³⁷ Texas Health and Human Services. (n.d.). [Pediatric palliative care.](https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers/pediatric-palliative-care)

<https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers/pediatric-palliative-care>

³⁸ Texas Health and Human Services. (n.d.). [Palliative care for providers.](https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers)

<https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers>

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.

Draft 2022 PCIAC Report Recommendations

Policy Issue: Establishment of a Supportive Palliative Care 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. Supportive palliative care (SPC) 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 (NASHP), less than 5% of patients with serious illness who could benefit from SPC actually receive it.³⁹

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 (HC), 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.⁴⁰ 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

³⁹ 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/)

<https://www.nashp.org/palliative-care-a-primer-for-state-policymakers/>

⁴⁰ Samantha, Smith; et al. (n.d.). [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

receive palliative care.⁴¹ 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.

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.^{42,43,44,45,46} 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 should direct patients to these pages for additional resources about SPC. Additional national SPC website resources which provide information and educational resources for both patients and providers include the Center to Advance Palliative Care (CAPC), the National Hospice and Palliative Care Organization (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

⁴¹ 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.

⁴² [Palliative Care](#). (n.d.). <https://www.hhs.texas.gov/services/health/palliative-care>

⁴³ [Hospice Care](#). (n.d.) <https://www.hhs.texas.gov/services/health/palliative-care/hospice-care>

⁴⁴ [Supportive Palliative Care](#) (n.d.). <https://www.hhs.texas.gov/services/health/palliative-care/supportive-palliative-care>

⁴⁵ [Palliative Care for Providers](#) (n.d.). <https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers>

⁴⁶ [Pediatric Palliative Care](#) (n.d.). <https://www.hhs.texas.gov/providers/health-services-providers/palliative-care-providers/pediatric-palliative-care>

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.

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.

Draft 2022 PCIAC Report Recommendations

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

There is no payment model in Texas to support the provision of palliative care⁴⁷ to pregnant women when their fetus is diagnosed with a terminal illness.⁴⁸ Currently, healthcare professionals provide these services with minimal or 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 (NIPT) 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 supportive palliative care (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

⁴⁷ Texas Health and Human Services describes [palliative care](https://www.hhs.texas.gov/services/health/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>

⁴⁸ 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.”

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 illness, the PCIAC strongly recommends the creation of policy and funding initiatives that will increase access to pediatric

palliative care, including prenatal services.^{49,50,51,52,53} 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 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 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 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.

⁴⁹ Schechtman, K., 2002. [Decision-making for termination of pregnancies with fetal anomalies: Analysis of 53,000 pregnancies](https://pubmed.ncbi.nlm.nih.gov/11814500/). *Obstetrics & Gynecology*, 99(2), pp.216–222. <https://pubmed.ncbi.nlm.nih.gov/11814500/>

⁵⁰ 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](https://pubmed.ncbi.nlm.nih.gov/15958151/). *Paediatric and Perinatal Epidemiology*, 19(4), pp.284–293. <https://pubmed.ncbi.nlm.nih.gov/15958151/>

⁵¹ [Western Australia Statistics – births, deaths, and marriages registered](https://www.wa.gov.au/organisation/departments-of-justice/the-registry-of-births-deaths-and-marriages/statistics-births-deaths-and-marriages-registered). <https://www.wa.gov.au/organisation/departments-of-justice/the-registry-of-births-deaths-and-marriages/statistics-births-deaths-and-marriages-registered>

⁵² [Texas Health Data, Live Births in Texas, 2005-2019](https://healthdata.dshs.texas.gov/dashboard/births-and-deaths/live-births). <https://healthdata.dshs.texas.gov/dashboard/births-and-deaths/live-births>

⁵³ [Texas Health Data, Deaths \(2006-2019\)](https://healthdata.dshs.texas.gov/dashboard/births-and-deaths/deaths-2006-2019). <https://healthdata.dshs.texas.gov/dashboard/births-and-deaths/deaths-2006-2019>

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.^{54,55,56}

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.⁵⁷

⁵⁴ Gans, D. et al., 2016. [Cost analysis and policy implications of a Pediatric Palliative Care Program](https://pubmed.ncbi.nlm.nih.gov/27233140/). *Journal of Pain and Symptom Management*, 52(3), pp.329–335.

<https://pubmed.ncbi.nlm.nih.gov/27233140/>

⁵⁵ 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](https://pubmed.ncbi.nlm.nih.gov/34981956/). *Journal of Palliative Medicine*, 25(7), pp.1031–1040.

<https://pubmed.ncbi.nlm.nih.gov/34981956/>

⁵⁶ 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?](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3619259/) *British Journal of Cancer*, 108(6), pp.1273–1279. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3619259/>

⁵⁷ 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.