



**Texas Palliative Care Interdisciplinary  
Advisory Council Recommendations to  
the 85th Texas Legislature**

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

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**November 2016**

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## About This Report

This report represents the considered input and views of the Palliative Care Interdisciplinary Advisory Council. The information contained in this document was discussed and voted upon at regularly scheduled meetings in accordance with the Texas Open Meetings Act. Details of these meetings, including agendas, documents, and meeting minutes are available at <https://hhs.texas.gov/about-hhs/leadership/advisory-committees/palliative-care-interdisciplinary-advisory-council>.

## Report Date

November 2016

## Acknowledgement

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## Palliative Care Interdisciplinary Advisory Council Members

The Palliative Care Interdisciplinary Advisory Council consists of 18 members appointed by the Health and Human Services Commission Executive Commissioner who are health care experts, including physicians, nurses, a social worker, a pharmacist, a spiritual professional, and advocates. Larry Driver, M.D. serves as the current chair of the Council. The current vice-chair is Barbara Jones, Ph.D, M.S.W. The Council also includes four ex officio, non-voting members representing state agencies.

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## **About the Palliative Care Interdisciplinary Advisory Council**

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

The Palliative Care Council performs the following tasks:

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

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## 1. Letter from the Chair

Dear Governor Abbott, Members of the Texas Legislature, and Health and Human Services Executive Commissioner Charles Smith:

*Quality of life.* This simple phrase conveys powerful but diverse meanings to different observers. While clinical researchers seek to quantify quality of life with objective metrics, we each have our own definition of the term related to our professional or personal perspectives. For those contending with life-altering or threatening health situations, quality of life assumes individual meanings to the individual persons dealing with those complex circumstances.

Likewise, *palliative care* implies parallel yet dissimilar situational meanings. At its core, palliative care is patient-centered, family-focused care that provides a patient with relief from the symptoms, pain, and stress of serious illness; is provided by an 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. A growing body of evidence shows that *supportive and palliative care* provided concurrent with curative treatment can help a patient recover from a serious illness more quickly and easily and also reduce medical costs. Similarly, *hospice palliative care* can help a patient facing the end of life make that transition with a lesser pain and symptom burden, with greater comfort and a better life nearing its end.

The intersection of palliative care and quality of life holds promise for better outcomes on multiple levels – for patients and families, for clinicians and other providers, for healthcare systems and society at large. In this era of the “Moonshot” initiative to end cancer along with other strategic initiatives addressing cardiovascular, respiratory, and renal diseases, Alzheimer’s and other neurodegenerative diseases, a common thread running through all of these is the need for interdisciplinary pain, stress, and symptom management that bolsters quality of life. Supportive and palliative care holds the potential to do that for major health adversities while adding distinct value to our healthcare system. This promise is worthy of our attention and efforts for Texas and beyond.

As set forth in H.B. 1874 from the 2015 84th Texas Legislature, the Texas Palliative Care Interdisciplinary Advisory Council is charged with assessing and defining relevant clinical, system, educational and policy issues, and with enhancing awareness and understanding of available resources, thereby enhancing access to available and appropriate care for patients. Those patients will be more aware of and have access to supportive and palliative care informed by the best available scientific evidence and delivered by appropriately educated and skilled interdisciplinary healthcare professionals.

This Council demonstrates how a diverse group of interdisciplinary stakeholders can collaborate with a shared, singular purpose – helping other people. This report and supporting information establishes the foundational launching pad for a *Supportive and Palliative Care Moonshot* aimed at enhancing the Quality of Life for patients and families dealing with pain and symptom distress from severe disease. Just as hospice palliative care helps those facing the end of life, supportive palliative care assists those persevering towards resuming life.

Sincerely,

A handwritten signature in black ink, appearing to read "L. Driver". The signature is fluid and cursive, with the first letter "L" being particularly large and stylized.

Larry C. Driver, M.D., Chair  
Palliative Care Interdisciplinary Advisory Council

## 2. Executive Summary

Palliative care is frequently misunderstood by health care professionals and the public as synonymous with hospice or "end of life" care. This misunderstanding prevents patients and families facing serious though not necessarily terminal illness from gaining appropriate access to palliative care services at the earliest moment when the services could be of benefit. To address this underutilization of patient and family focused palliative care, the Texas Legislature established the Palliative Care Interdisciplinary Advisory Council (Council), House Bill (H.B.) 1874, 84th Legislature, Regular Session, 2015. Council members, appointed by the Executive Commissioner of the Health and Human Services Commission (HHSC), hail from the disciplines of medicine, nursing, social work, pharmacy, ethics, and chaplaincy. Collectively, they form a leading panel of experts and practitioners well suited to study opportunities and make recommendations for improving palliative care services in Texas.

Members of this multidisciplinary council unanimously believe that palliative care should be recognized as having two branches: 1) Supportive and Palliative Care (SPC) and 2) Hospice Care (HC or Hospice). While Hospice addresses the terminal stage of serious illness when no further curative or life-prolonging therapy is available or desirable, SPC services may be appropriate for patients and families at any stage of a serious illness, including in the early stages of the illness. SPC services may be combined with aggressive efforts to treat or cure disease. This report, the first issued by the Council, focuses primarily on ideas to improve awareness of and access to SPC services.

Numerous peer-reviewed studies on the benefits of timely SPC services convincingly demonstrate that:

- Patients endure less pain and other suffering,<sup>1</sup> have fewer hospital readmissions,<sup>1</sup> survive longer for diagnoses of metastatic cancer,<sup>2</sup> receive fewer non-beneficial interventions,<sup>3</sup> have shorter intensive care unit (ICU) lengths of stay,<sup>4</sup> and receive treatments more congruent with their wishes.<sup>5</sup>
- Families experience reduced surrogate decision maker conflict and emotional distress with advance care planning,<sup>6</sup> improved family (and patient) satisfaction, less depression, better bereavement, and less post-traumatic stress symptoms when a seriously ill family member dies.<sup>7</sup>

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<sup>1</sup> Lorenz K, Lynn J, et al. *Ann Intern Med*. 2008; 148: 147-159; Wagner-Johnson N, Carson K, Grossman S. *JPSM*. Feb 2010; 39 (2):180-185; Purcell WT, Grossman SA, et al. Abstract No. 2963, *Proc Am Soc Clin Oncol* 22: 2003; Riolfi M, Buja A, et al. *Palliat Med*. 2014 May; 28(5):403-411.

<sup>2</sup> Temel JS, Greer JA, et al. *NEJM* 2010;363:733-42; Bakitas M, Tosteson T, et al. *J Clin Oncol* 32:5s, 2014 (suppl: abstr 9512) Lilly CM, De Meo DL, et al. *Am J Med*. 2000; 109: 469-475.

<sup>3</sup> Purcell WT, Grossman SA, et al. Abstract No. 2963, *Proc Am Soc Clin Oncol* 22: 2003.

<sup>4</sup> Norton SA, Hogan LA, et al. *Crit Care Med*. 2007 Jun;35 (6):1530-5; Campbell ML, Guzman JA. *Chest*. 2003 Jan; 123(1):26-71.

<sup>5</sup> Lautrette A, Darmon M, et al. *NEJM*, Feb 2007, 356(5), 469-478.

<sup>6</sup> Chiarcharo J, Praepannaral B et al. *Annals ATS*. 2015, 12(10):1528-1532; Allen RS, Allen JY, et al. *JAGS*. 2008, 56(10):1904-1909.

<sup>7</sup> Cassarett D, Packard A, et al. *J Am Geriatr Soc*. 2008;56:593-99; Dionne-Odom JN, Anres A, et al. *J Clin Oncol* 32:5s,2014 (suppl: abstr LBA9513); Heyland DK, Allan DE, et al. *Open Medicine*. 2009, 3(2): 101-110.

- Payers, whether commercial, governmental, or private, see significantly lower costs – especially with early SPC consultation.<sup>8</sup>

Despite these benefits, as of 2014, only 43 percent of Texas hospitals with 50 or more beds offered organized SPC services, far below the national rate of 67 percent.<sup>9</sup> The Council's review of available evidence also finds that the state faces a significant shortage in the number of interdisciplinary professionals with a specialized palliative care credential as well as a deficiency in the number of practitioners in other specialties having adequate knowledge and training in the area of palliative care. Moreover, some areas of Texas, such as the Rio Grande Valley, El Paso, and the easternmost region of the state appear to be particularly disadvantaged with regard to the availability of palliative care infrastructure. To address these barriers and encourage increased utilization of patient and family focused palliative care at earlier stages of serious illness, the Council makes the following recommendations:

1. HHSC should employ educational resources to clearly explain, delineate, distinguish between, and promote the “two branches” definition of Palliative Care, that is, supportive and palliative care and hospice care. The two branch definition will lead to earlier access to supportive and palliative care services at any stage of serious illness. The unit of treatment for SPC should be the patient and the family.
2. Moderate and large sized hospitals in the state should offer interdisciplinary SPC services at all stages of serious illness. To address the workforce and technical capacity requirements needed to expand SPC services across the state, the Legislature (through regulation, licensing, and/or financial incentives) should encourage individual professional and facility certifications in palliative medicine (the Council recommends the same for hospice medicine).
3. The number of palliative care providers is small, while the needs are great. State policy should support health care professionals' efforts to earn and maintain specialized palliative care credentials by, for example, expanding fellowship and continuing education opportunities. However, simply increasing the number of specialists in the field of palliative care is not enough. Palliative care training and continuing education should be widely available for all relevant interdisciplinary professionals, including medical specialists who care for seriously ill patients, family physicians, advanced practice providers (APPs), nurses, social workers, and chaplains, among others.<sup>10</sup> Health care system boards of directors, administrators, and other leaders play a crucial role charting the course for health care in

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

<sup>9</sup> National Palliative Care Report Card, available at [www.capc.org](http://www.capc.org) and [www.npcrc.org](http://www.npcrc.org).

<sup>10</sup> The Council recognizes a wide spectrum of professions care for hospice and palliative care patients. These professions include, but are not limited to, oncologists, cardiologists, nephrologists, family physicians, advanced practice providers (APPs), nurses, social workers, chaplains, certified nurse aids, respiratory therapists, speech therapists, occupational therapists, physical therapists, psychiatrists, and psychologists, among others.

Texas and should be offered education and outreach on the positive impacts of providing supportive and palliative care in their hospitals and networks.

4. As the availability of palliative care services expands across Texas, the Legislature, HHSC, and industry groups must ensure providers meet the highest standards for quality and avoid conflicts of interest. Both hospitals with SPC teams and hospice providers should participate in one or more of the National Quality Forum Palliative Care and End-of-Life Quality Measures. HHSC should collaborate with stakeholders to develop a palliative and hospice scorecard. The state should evaluate projects related to palliative care as part of the Delivery System Reform Incentive Payment (DSRIP) program and identify initiatives and performance measures which show the greatest potential for positive change. Where possible, HHSC should make performance measures and educational resources about palliative care quality available to providers and industry groups, as well as to patients and families.
5. HHSC, the Texas Hospital Association (THA), Texas Medical Association (TMA), Texas Nurses Association (TNA), National Association of Social Workers (NASW), and Texas Academy of Physician Assistants (TAPA), and the Social Work Hospice and Palliative Care Network (SWHPN) and other industry stakeholders should partner to develop and promote effective technical assistance resources for hospitals seeking to establish or enhance their supportive and palliative care programs and for professionals seeking an SPC related certification. This technical assistance could take the form of a web based library of model policies, practices, and protocols.

In addition to recommendations, the Council offers, as part of this report, a consensus statement related to policies, practices, and protocols concerning patients' rights to information about palliative care. This statement addresses the following four questions posed by the Legislature through H.B. 1874:

1. May a palliative care team member introduce palliative care options to a patient without the consent of the patient's attending physician?
2. What practices and protocols should be followed for discussions between a palliative care team member and a patient on life-sustaining treatment?
3. What practices and protocols should be followed for discussions between a palliative care team member and a patient in regards to advance directives?
4. What practices and protocols on informed consent and disclosure requirements for palliative care services should be followed?

Although some state legislatures have mandated specific information about palliative care be shared with patients, the Council does not propose any changes in state law in response to these

questions.<sup>11</sup> However, the Council does hope its statement contributes to the adoption of best practices for SPC programs across the state. The Council's statement includes the following key points:

- SPC is a recognized specialty in the medical field, and SPC consultations should generally follow the same protocols as other consultations (e.g. cardiology, oncology, infectious disease, etc.).
- Palliative care professionals and other professionals should avoid forcing a serious illness discussion on a patient, family, or surrogate, and, at every step in a conversation about supportive and palliative care, permission should be obtained from the patient/family/surrogate before proceeding.
- SPC professionals must not assume a discussion regarding goals of care will lead to limitations on life sustaining treatments but instead may lead to aggressive treatments.
- If a patient agrees to a discussion about goals of care and advance directives, his or her preferences should be clearly documented, preferably in a living will or in a living will in conjunction with a medical power of attorney (MPOA).

H.B. 1874 charges the Council to advise HHSC on the operation of an education and information program for patients, families, and professionals. In this regard, the Council intends to play a tangible role leveraging the full range of its expertise to support two program initiatives:

**Palliative Care Information Website:** The Council will take on key responsibilities for governing the palliative care information website authorized by H.B. 1874, in particular by routinely vetting and recommending specific content to be posted to the site. This quality control function performed by leading professionals in the field in conjunction with regular opportunities for public comment will ensure information posted by HHSC into the public domain meets the highest standards and reflects a consensus view among interdisciplinary palliative care professionals in Texas.

**Continuing Education Program:** The Council plans to contribute directly to furthering continuing education (CE) related to palliative care in Texas. Initially, the Council's work in this area will focus on improving skills and knowledge among a wide range of practitioners by identifying and publicizing existing palliative care CE opportunities, identifying speakers to appear at events across the state, and periodically hosting its own educational events (in conjunction with a Council quarterly meeting). The Council will also explore options to create, maintain, and host enduring educational materials on the Palliative Care Information Website or to share content for partners to administer and host.

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<sup>11</sup> In May 2016, the New York State Legislature passed the Palliative Care Information Act which requires physicians and nurses to inform terminally ill patients about palliative care and end of life options.



The Texas Legislature established the Palliative Care Interdisciplinary Advisory Council to provide objective evaluation and consensus recommendations to increase the availability of patient and family focused palliative care in Texas and to assist HHSC with the establishment and operation of an ongoing palliative care information and education program. Over the course of 2016, the Council has pursued these charges in full public view and in partnership with the many stakeholders committed to improving palliative care services in Texas. The Council's assessment confirms the Legislature's belief that significant and broad improvements in palliative care are possible in Texas and such improvements will contribute to better outcomes, higher satisfaction, and smarter spending for patients, families, and payers. The Council hopes this initial report will serve as a catalyst for a sustained quality improvement effort and looks forward to continuing its work to make Texas a national leader for providing appropriate, compassionate, and high quality palliative care to patients and families at any age and any stage of serious illness.

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### 3. Introduction

The medical aphorism, “To cure sometimes, to relieve often, to comfort always” remains true to this day, and we have certainly never had greater ability to cure than now. When a cure is no longer possible, we have never had better comforting powers than those available through hospice and palliative care services. Despite the wide spread and growing availability of high tech curative interventions and the well-established high touch comforting powers of hospice, three major deficits have remained stubbornly persistent in the care of seriously ill patients:

- Severe, poorly treated pain in approximately half of hospitalized patients, so ill they have a 50 percent six month mortality rate, as well as general confusion between patients and physicians about patient goals of care;<sup>12</sup>
- High variability in intensity of treatment in the last months to years of life with some patients subjected to three to six times as much medical intervention as others without better outcome.<sup>13</sup> This is considered a non-beneficial intervention; and
- Extremely high costs with personal bankruptcy for 25 percent of Medicare patients in the last five years of life, a financial disaster for surviving family members,<sup>14</sup> and 25 to 30 percent of annual Medicare spending for the 5 percent of Medicare patients who die each year.<sup>15</sup>

In addition to these deficits, the Council identified a number of potential barriers affecting Texans' access to patient and family focused palliative care, including:

- Confusion and misunderstanding regarding the definition, goals, and benefits of palliative care among patients, families, providers, and administrators, as members of the Council from across the state report that palliative care is frequently thought to be synonymous with end-of-life care. This misunderstanding prevents patients and families facing serious, though not necessarily terminal illness from gaining appropriate access to palliative care services at the earliest moment when the services could be of benefit. To reduce confusion, members of the Council unanimously agree that palliative care should be recognized as having two branches: 1) Supportive and Palliative Care (SPC) and 2) Hospice Care (HC or Hospice). While Hospice addresses the terminal stage of serious illness when no further curative or remissive therapy is available or desirable, SPC services may be appropriate for patients and families at any stage of a serious illness, including in the early stages of the illness.
- Shortages of specialized resources to deliver palliative care services, as the number of hospitals offering interdisciplinary supportive and palliative care services along with the

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<sup>12</sup> The SUPPORT Study. *JAMA* 1995; 274:1591-98 565-576.

<sup>13</sup> Multiple periodically updated reports and analysis available at [www.dartmouthatlas.org](http://www.dartmouthatlas.org).

<sup>14</sup> Kelley AS, McGarry K, Fahle S, et al. *J Gen Intern Med*. 2013 Feb; 28(2):304-9.

<sup>15</sup> Riley GF, Lubitz JD. *Health Serv Res*. 2010; 45(2):565-76.

supply of professionals with specialized training in palliative care is low relative to need for both adults and children in Texas. Disparities in this area are particularly pronounced in the El Paso, Rio Grande Valley, and East Texas areas of the state.

- Lack of palliative care training among front line health professionals, as the National Academy of Sciences reports, "the number of hospice and palliative care specialists is small, which means the need for palliative care also must be met through primary care."<sup>16</sup> In fact, a recent, credible national survey found that three quarters of primary care physicians understand they have this responsibility.<sup>17</sup> Even so, less than one-third of primary care physicians report any formal training or continuing education in key areas of palliative care such as how to initiate or have goals of care conversations with patients and families<sup>18</sup> or the appropriate use of opioids.<sup>18</sup> In Texas, the Council could identify few palliative and supportive care related continuing education opportunities targeted to an audience of general health care interdisciplinary practitioners.
- Financial barriers inherent to most current provider reimbursement models, as the palliative care model, like other care models that integrate health and social services, is not well supported by most insurance benefit designs or by the programs, Medicare and Medicaid, which serve the great majority of individuals with advanced serious disease.

A review of available evidence indicates initiatives to expand access to and utilization of supportive and palliative care services hold significant potential for improving patient satisfaction, health outcomes, and the cost of health care in Texas. Numerous peer-reviewed studies on the benefits of timely SPC services demonstrate that:

- Patients endure less pain, other suffering, and readmissions;<sup>19</sup> often survive longer for diagnoses of metastatic cancer with a better quality of life;<sup>20</sup> receive fewer non-beneficial interventions;<sup>21</sup> have shorter ICU lengths of stay;<sup>22</sup> and receive treatments more congruent with their wishes.<sup>23</sup>
- Families experience reduced surrogate decision maker conflict and emotional distress with advance care planning,<sup>24</sup> improved family (and patient) satisfaction, less depression,

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<sup>16</sup> Committee on Approaching Death: Addressing Key End of Life Issues; Institute of Medicine. *Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life*. Washington (DC): National Academies Press (US); 2015 Mar 19. Summary available from: <http://www.ncbi.nlm.nih.gov/books/NBK285667/>.

<sup>17</sup> Ostrov, B. Most Doctors Unsure How To Discuss End-of-Life Care, Survey Says. Retrieved from <http://khn.org/news/most-doctors-unsure-how-to-discuss-end-of-life-care-survey-says/>.

<sup>18</sup> Ury W, et al. *J Gen Intern Med*, 2002; 17(8): 625-31.

<sup>19</sup> Lorenz K, Lynn J, et al. *Ann Intern Med*. 2008; 148: 147-159; Wagner-Johnson N, Carson K, Grossman S. *JPSM*. Feb 2010; 39 (2):180-185; Purcell WT, Grossman SA, et al. Abstract No. 2963, *Proc Am Soc Clin Oncol* 22: 2003; Riolfi M, Buja A, et al. *Palliat Med*. 2014 May; 28(5):403-411.

<sup>20</sup> Temel JS, Greer JA, et al. *NEJM* 2010;363:733-42; Bakitas M, Tosteson T, et al. *J Clin Oncol* 32:5s, 2014 (suppl: abstr 9512).

<sup>21</sup> Morrison, RS, Penrod JD, et al. *Arch Intern Med*. 2008; 168(16):1783-1790.

<sup>22</sup> Norton SA, Hogan LA, et al. *Crit Care Med*. 2007 Jun; 35(6):1530-5; Campbell ML, Guzman JA. *Chest*. 2003 Jan; 123(1):26-71

<sup>23</sup> Lautrette A, Darmon M, et al. *NEJM*, Feb 2007, 356(5), 469-478.

<sup>24</sup> Chiacharo J, Praepannaral B et al. *Annals ATS*. 2015, 12(10):1528-1532; Allen RS, Allen JY, et al. *JAGS*. 2008, 56(10):1904-1909.

better bereavement, and fewer symptoms of post-traumatic stress disorder (PTSD) when a seriously ill family member dies.<sup>25</sup>

- Payers, whether commercial, governmental, or private, see significantly lower costs – especially with early SPC consultation.<sup>26</sup>

To realize these benefits, Texas will need to increase its capacity to deliver SPC services. Data from the Center to Advance Palliative Care (CAPC) shows that Texas lags behind the national average on the availability of hospital based palliative care services. The CAPC 2015 Report Card (based mainly on data from 2013) awarded Texas a "C" rating, compared to a "B" rating for the U.S. overall.<sup>27</sup> More specifically, CAPC found that only 43 percent of Texas hospitals with 50 or more beds offered organized palliative care services, far below the national rate of 67 percent.<sup>27</sup> Texas performance on this indicator is basically unchanged from four years earlier (2011 Report Card) when 42 percent of the state's hospitals reported a palliative care program.<sup>27</sup>

To better understand the implications of the CAPC analysis, HHSC staff, at the direction of the Council, reviewed Texas specific data on palliative care services reported as part of the American Hospital Association (AHA) Annual Survey of Hospitals. These AHA survey data are the primary--though not the only--source used by CAPC to compile its report card metric. Using only the AHA data, Texas staff largely corroborated the CAPC result for the state (see Table 1).

Table 1. Texas CAPC Guide

Source	Data Year	Grade	Total Programs/ Hospitals (≥ 50 beds)	> 300 beds
CAPC National	2012/ 2013	67%	(1,591/2,393)	90% (659/732)
CAPC Texas	2012/ 2013	43%	(85/198)	66% (37/56)
In-house Texas	2014	42%	(86/205)	71% (42/59)

Note: Results are based on CAPC cohort definitions (see technical note in footnote below).<sup>28</sup>

<sup>25</sup> Cassarett D, Packard A, et al. *J Am Geriat Soc.* 2008;56:593-99; Dionne-Odom JN, Anres A, et al. *J Clin Oncol* 32:5s,2014 (suppl: abstr LBA9513); Heyland DK, Allan DE, et al. *Open Medicine.* 2009, 3(2): 101-110.

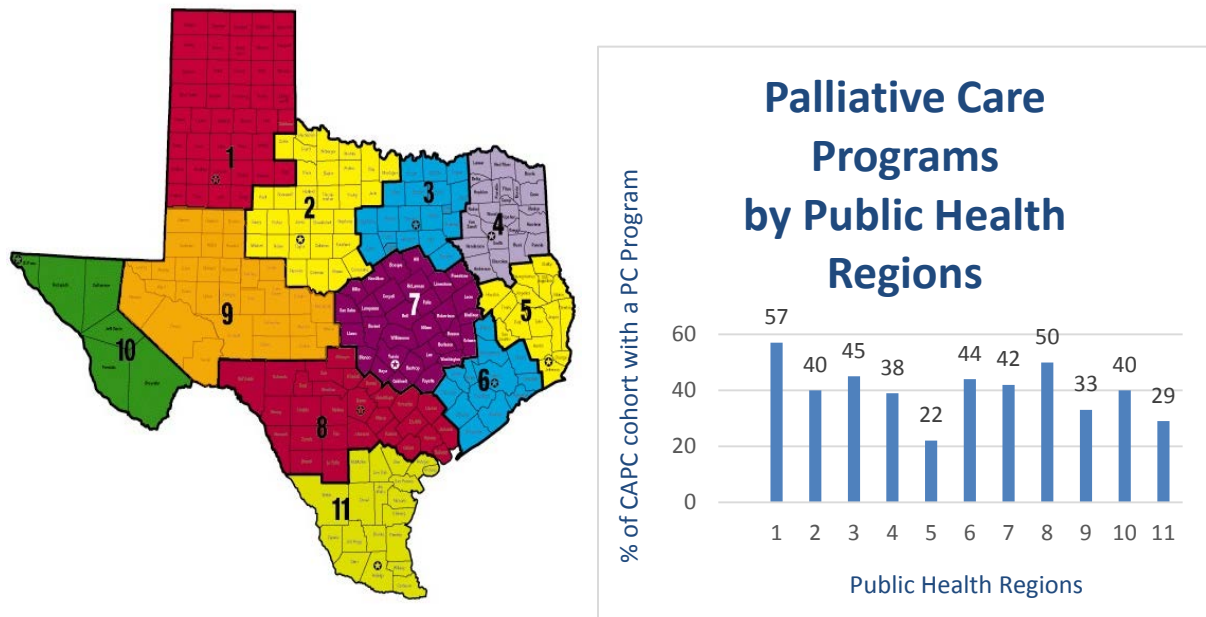
<sup>26</sup> Morrison, RS, Penrod JD, et al. *Arch Intern Med.* 2008; 168(16):1783-1790; Penrod JD, Deb P, et al. *J Palliat Med.* 2010 Aug; 13(8):973-79; Morrison RS, Dietrich J, et al. *Health Affairs.* 2011 Mar; 30(3):454-63; McCarthy I, Philastre MR, Fine RL, et al. *Health Services Research.* 2015; 50(1): 217-236; May P, Garrido MM, Cassell JB, et al. *J Clin Oncol.* 2015, 33(25): 2745-2752; Sweeney L, Halpert A, et al. *Am J Manag Care.* 2007 Feb; 13(2):84-92.

<sup>27</sup> National Palliative Care Report Card, available at [www.capc.org](http://www.capc.org) and [www.nperc.org](http://www.nperc.org).

<sup>28</sup> Analyses were limited to general medical and surgical, cancer, or heart hospitals with fifty or more licensed beds based on data from the American Hospital Association Annual Survey of Hospitals. Veterans Administration and Indian Health Service facilities were excluded. CAPC method does not clearly distinguish hospital run palliative care programs from contracted hospice services.

HHSC staff further reviewed the AHA data to examine the availability of hospital palliative care programs in Texas at a more granular level than reported by CAPC. This analysis, in particular, suggests that access to palliative care services varies significantly from community to community across the state. As shown below (Figure 1), a much lower percentage of hospitals in Public Health Regions 5 (East Texas) and 11 (Rio Grande Valley) offer palliative care services than hospitals in other parts of the state. No Texas region, however, is close to the national rate.

Figure 1. Texas Palliative Care (PC) Programs by Public Health Region (PHR), 2014



PHR	# Hospitals (50 or more beds)	# with PC Program	% with PC Program
1	7	4	57%
2	5	2	40%
3	60	27	45%
4	13	5	38%
5	9	2	22%
6	41	18	44%

PHR	# Hospitals (50 or more beds)	# with PC Program	% with PC Program
7	24	10	42%
8	18	9	50%
9	6	2	33%
10	5	2	40%
11	17	5	29%
Total	205	86	42%

Analysis of AHA data also reveal potential disparities faced by residents living in less populated areas of the state. In 2014, only 16 percent of non-metro hospitals with greater than 50 beds offered palliative care services compared to 47 percent in metro areas (Table 2).

*Table 2. Palliative Care: Metro vs. Non-Metro Hospitals*

Source	Data Year	*Metro	Non-Metro
CAPC Texas	2012/ 2013	NA	NA
In-house Texas	2014	47% (81/173)	16% (5/32)

\*According the Office of Management and Budget, a metropolitan statistical area contains at least one urbanized area of 50,000 or more population plus adjacent territory with a high degree of social and economic integration with the core as measured by commuting ties.

The state faces significant challenges to meet the workforce needs to expand palliative care services to reach the national average. These challenges appear particularly noteworthy for Public Health Regions 10 (El Paso) and 11 (Rio Grande Valley). Data provided by the Health Professions Resource Center, Center for Health Statistics at the Department of State Health Services, show that the state's most populated border regions have fewer than half the number of physicians per population credentialed in palliative medicine as the state overall (see Table 3 on next page).

Overall, only 275 Texas physicians hold a certification for Hospice and Palliative Medicine. This relatively low number of credentialed professionals mirrors findings across other palliative care related disciplines:

- Only 19 physicians statewide hold a Certified Hospice Medical Director credential from the Hospice Medical Director Certification Board;
- A total of 46 Advanced Practice Registered Nurses in Texas hold an Advance Certified Hospice and Palliative Nurse certification; and
- Currently, 20 fellows are in a palliative medicine position statewide.

*Table 3. Physicians with Primary or Secondary Certification in Hospice and Palliative Medicine as of October 1, 2015*

Public Health Region	# Credentialed Physicians	# per 100,000 population (age 18 years and older)	# per 100,000 population (age 65 years and older)
1	9	1.4	7.7
2	7	1.6	7.3
3	62	1.1	7.9
4	12	1.3	5.9
5	10	1.6	7.7
6	74	1.5	10.8
7	41	1.6	10.9
8	36	1.7	9.5
9	11	2.5	13.5
10	3	0.5	2.9
11	10	0.6	3.7
Totals	275	1.3	8.5

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

With these issues in mind, the Texas Legislature established the Palliative Care Interdisciplinary Advisory Council to “assess the availability of patient-centered and family-focused palliative care in this state” and recommend policies to promote increased access to services. As a first step to meet this charge, in this inaugural report, the Council provides advice to state and HHSC leadership as well as to industry stakeholders working to improve palliative care and health care generally in Texas. As part of that guidance, the Council:

1. Provides clarification to the definition of palliative care and encouragement for referring to non-hospice outpatient ambulatory, home based, and hospital based palliative care as “Supportive” care or “Supportive and Palliative Care” (SPC).
2. Recommends evidence and consensus based policies and practices to foster the establishment, maintenance, and operation of patient centered, family focused palliative care, as distinct from hospice, as well as to allow the state to meet the workforce and technical capacity requirements for expanding palliative care programs across the state.



3. Identifies important opportunities for increasing training, awareness, and continuing education related to supportive and palliative care to general practitioners; other doctors including but not limited to oncologists, cardiologists, geriatricians, intensivists, and other specialists who care for seriously ill patients; nurses; advanced practice professionals; social workers; chaplains; allied health professionals; community health workers;<sup>29</sup> and administrators.
4. Emphasizes the importance of ensuring that providers for both SPC and hospice services meet the highest standards for quality and transparency and avoid conflicts of interest.
5. Recommends organizations and resources where model policies and protocols for technical assistance for SPC may be developed and obtained.
6. Answers specific questions posed by the Texas Legislature in H.B. 1874 related to patient rights to information about palliative care.
7. Describes how the Council will leverage the expertise of its members to directly support two initiatives for the new palliative care education and information program established by H.B. 1874: the creation of a palliative care information website and the administration of a program to increase continuing education opportunities among interdisciplinary professionals.

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<sup>29</sup> According to the Texas Department of State Health Services, community health worker responsibilities could include health education, outreach, patient navigation, informational counseling, and social support, among others. See the DSHS Community Health Workers - Promoter(a) or Community Health Worker Training and Certification Program for more information, [http://dshs.texas.gov/mch/chw/Community-Health-Workers\\_Program.aspx](http://dshs.texas.gov/mch/chw/Community-Health-Workers_Program.aspx).

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## 4. Recommendations

The following recommendations address the definition of palliative care, establishing interdisciplinary palliative care programs in hospitals, developing the workforce and technical capacity to support these programs, and promoting the highest standards for quality. The focus of our recommendations is primarily on supportive and palliative care (SPC), but whether service is provided earlier in the course of serious illness via an SPC team or later in the course of clearly terminal illness by a hospice team, the service should be STEEEP based (Safe, Timely, Effective, Efficient, Equitable, Patient Centered).

### Recommendation I: Promote the Two-Component Definition of Palliative Care

We recommend HHSC employ educational resources to promote the two-component definition of palliative care, in particular the concept of supportive and palliative care. Considerable confusion exists about the meaning of palliative care, which like many medical terms has a Latin root, in this case *palliativus*, meaning to cloak or conceal pain and other suffering. Palliative care is frequently confused with hospice, which in the United States is a Medicare benefit defining a special way of caring for people in the late stage of terminal illness. In contrast, palliative care is an approach that improves the quality of life of patients and their families facing serious, even life threatening, though not necessarily terminal illness. Palliative care occurs most effectively through the prevention and relief of suffering by means of early identification, assessment, and treatment of pain and other physical, psychosocial, and spiritual problems. It may be delivered in conjunction with life-prolonging and often curative therapy.

Confusion between hospice and palliative care may lead to late referrals of patients by physicians and late acceptance of palliative care by patients and/or families. Late referral deprives all parties, but most importantly the patient and family, of the many benefits of palliative care enumerated in this report. Definitions of palliative care have been offered by several organizations, including the American Cancer Society, Center to Advance Palliative Care, the National Quality Forum, the Joint Commission, the Institute of Medicine, and others, yet confusion remains about just what palliative care means. Some have argued that the name should be changed to “Supportive Care,” and researchers at the MD Anderson Cancer Center have formally researched the power of the word “supportive” in relation to palliative care.<sup>30</sup> Others, such as Baylor Scott and White Health (nationally recognized by the American Hospital Association and Joint Commission for excellence in palliative care) have formally adopted the terminology of “Supportive and Palliative Care” to describe their palliative care service line.

With the above in mind, the Council recommends that HHSC, the Legislature, health care professionals, and other health care providers recognize palliative care as having two branches: 1) Supportive and Palliative Care (SPC) and 2) Hospice Care. We believe this distinction is essential in helping all receive the full benefits of palliative care, but especially the benefits of *early SPC consultation* on survival for metastatic cancer patients<sup>31</sup> and improved cost control.<sup>32</sup>

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<sup>30</sup> Fadul N, Elsayem A, Palmer L et al. *Cancer*. 2009 May; 115(9):2013-2021.

<sup>31</sup> Temel JS, Greer JA, et al. *NEJM* 2010;363:733-42; Bakitas M, Tosteson T, et al. *J Clin Oncol* 32:5s, 2014 (suppl: abstr 9512).

We define supportive and palliative care as an interdisciplinary team based process designed to relieve suffering and improve quality of life for patients *and families* facing **serious though not necessarily terminal illness**. SPC should be available at any stage of serious illness from birth to old age. SPC may be offered simultaneously with disease modifying interventions, including attempts at cure or remission, thus distinguishing it from hospice care. SPC should be available across all sites of care, though most SPC services will be provided in the hospital or ambulatory/office setting with lesser amounts in the home or nursing home setting. The suffering addressed by SPC teams may be physical (pain, shortness of breath, nausea, etc.), emotional (depression, anxiety, fear), social (family/community distress), and/or spiritual. SPC teams should acknowledge that quality of life is unique to each individual and what is unacceptable to one person may be quite acceptable to another. HHSC should direct the public to evidence based, non-commercial, patient friendly websites explaining the benefits of SPC such as [www.CAPC.org](http://www.CAPC.org).

The second branch of palliative care is Hospice Care (HC). Unlike SPC, which is delivered in the context of prognostic uncertainty, HC should be available for the terminal stage of serious illness when no further curative or life-prolonging therapy is available, the patient no longer wishes to pursue cure or remission, and death is almost certain to occur within a defined period of time. HC should be available across all sites of care, although most hospice services are delivered in the home or nursing home setting. HC is a defined benefit program within Medicare and some commercial insurance programs, typically covering interdisciplinary team services through a per diem payment mechanism.

Unlike many branches of medicine, we believe the “unit of treatment” for SPC (or HC) is the patient and family. When a patient has a serious illness, it often has a profound impact on family members, including young children of seriously ill adults (parents, grandparents, or any other important adult in a child’s life). Thus, HHSC should collect and make available informational resources for seriously ill adults and their families that will provide better support for children in those families. The Legislature should explore regulatory, licensing, and/or financial incentives for hospitals to provide supportive services for the families of seriously ill patients, including services from Child Life Specialists, chaplains, social workers, and other supportive specialists.

We recommend HHSC and the Legislature drop the concept of patient as “consumer” from Chapter 118, Texas Health and Safety Code, the statute authorizing the Council and the palliative care education program. Consumer implies the laws of the market place - caveat emptor (buyer beware). Especially in the field of palliative care, it is important to remember the meaning of “patient” as “one who suffers” and as a person to whom the healing professions have certain fundamental moral obligations, including the promotion of the welfare of the patient at all times, including when cure or remission are no longer possible.

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<sup>32</sup> The Council identifies at least 14 studies demonstrating the link between early SPC consultation on improved cost control including: Morrison RS, Dietrich J, et al. *Health Affairs*. 2011 Mar; 30(3):454-63; McCarthy I, Philastre MR, Fine RL, et al. *Health Services Research*. 2015; 50(1): 217-236.

## Recommendation II: Expand SPC Programs in Texas

We recommend the Legislature consider regulatory, licensing, and reimbursement incentives to effectively promote the establishment of adult and pediatric supportive and palliative care services across Texas. We encourage all Texas hospitals with at least 100 adult beds to develop the capacity to provide adult interdisciplinary SPC. Telemedicine options for SPC services should be made available in smaller facilities with under 100 adult beds.

Pediatric palliative care is modeled on the principles of adult palliative care, but there are differences between treating seriously ill children and adults, giving pediatric SPC its own unique set of challenges. For example, a significant number of children with complex chronic conditions face genetic and neurological disease that in previous generations were fatal. Because of medical advances and technology, their lives have been extended, and pediatric SPC is often delivered for a far longer period and with a much wider range of specialists than required for adult SPC. While we cannot recommend the establishment of pediatric SPC programs in all Texas community hospitals at the current time, we encourage and urge the establishment of fully functional interdisciplinary pediatric SPC programs at all pediatric tertiary care centers and at any community hospital that routinely treats children with a complex chronic condition, defined as any medical condition that can reasonably be expected to last at least 12 months unless death intervenes or that involves either multiple organ systems or one organ system severely enough to require specialty pediatric care, with a likelihood of some period in a tertiary care center.

We recommend the Legislature encourage but not require individual professional and facility certifications in SPC via regulation, licensing, and/or financial incentives. (We recommend the same for hospice medicine). Supportive and palliative care requires an interdisciplinary team approach. Such teams are labor intensive and reimbursement poor, they do not receive the per diem payments hospices receive, and yet they clearly save payers money, including Medicaid.<sup>33</sup> Unfortunately, for Texas Medicaid and other payers, over 50 percent of hospitals still lack SPC programs. To remedy that deficiency, we recommend that the Legislature incentivize the creation of hospital based SPC teams via small additional Medicaid payments to hospitals with a full interdisciplinary SPC team and a larger payment if that hospital based team is Joint Commission certified.

Although SPC services are provided by an interdisciplinary team, payment is available from Medicare and/or commercial payers only for the medical professional members of the team (physician and/or advance practice professional such as a nurse practitioner or physician assistant). The Legislature should explore regulatory, licensing, and/or financial incentives for hospitals to provide full interdisciplinary SPC teams with a minimum core team of physician, advance practice professional (APRN, PA), social worker, and chaplain. Some pioneering organizations, including Baylor Scott and White Health, have extensive experience with Child Life services for the children of seriously ill adults and believe that Child Life Specialists should be part of the core SPC team, but this is not yet considered a national standard of care.

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<sup>33</sup> Morrison RS, Dietrich J, Ladwig S, et al. *Health Affairs*. March 2011; 30 (3):454-463).

Palliative medicine has a sufficient knowledge base and skill set such that the American Board of Medical Specialties (ABMS) recognizes it as a specialty, just as it recognizes other specialties such as surgery, family practice, cardiology, or oncology. Hospice medicine shares that skill set but also offers the opportunity for a hospice physician to become a board certified hospice medical director. We recommend that Texas Medicaid encourage these certifications by offering additional reimbursement to board certified providers of either SPC or Hospice, whether those providers are physicians, advanced practice professionals, or other human service professionals.<sup>34</sup>

We recommend HHSC maintain a directory for patients and families of Joint Commission certified SPC programs, Joint Commission certified hospice programs, Community Health Accreditation Partner (CHAP) accredited hospice programs, American Board of Medical Specialties hospice and palliative care certified clinicians, where it exists, and hospice and palliative care certified APPs in Texas. We recommend that HHSC note whether the physicians or APPs serving on SPC or hospice teams are ABMS certified in hospice and palliative medicine. We recommend that in the case of hospice, HHSC report whether or not the hospice medical director is a Certified Hospice Medical Director and whether or not the hospice and palliative administrator is certified. In order to maintain the public trust related to the important distinctions between SPC and Hospice, we recommend complete transparency as to whether a physician providing supportive and palliative care consultation is employed by a hospice company, a hospital, or some other medical group.

### **Recommendation III: Increase SPC Training and Awareness for All Health Care Professionals**

The number of palliative care providers is small, while the needs are great. State policy should support health care professionals' efforts to earn and maintain specialized palliative care credentials by, for example, expanding fellowship and continuing education opportunities. However, simply increasing the number of specialists in the field of palliative care is not enough. Palliative care training and continuing education should be widely available for all relevant interdisciplinary professionals, including medical specialists who care for seriously ill patients, family physicians, advanced practice providers (APPs), nurses, social workers, and chaplains, among others.<sup>36</sup> This Council, for example, in partnership with HHSC, the Department of State Health Services (DSHS), and industry stakeholders intends to develop continuing education offerings targeted to a general health care professional audience. In addition, the Legislature, HHSC, and the industry should explore opportunities to expand peer to peer learning programs among professionals and to include curriculum in training programs for nontraditional health workers, such as community health workers, that enhances their ability to promote greater awareness of SPC services.<sup>35</sup>

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<sup>34</sup> The Council recognizes that a wide spectrum of professions provide hospice and palliative care. These professions include but are not limited to Oncologists, Cardiologists, Nephrologists, family physicians, advanced practice providers (APPs), nurses, social workers, chaplains, certified nurse aids, respiratory therapists, speech therapists, occupational therapists, physical therapists, psychiatrists, and psychologists, among others.

<sup>35</sup> According to the Texas Department of State Health Services, community health worker responsibilities could include health education, outreach, patient navigation, informational counseling, and social support, among others. See the DSHS Community Health Workers -

Hospital leaders and administrators play a crucial role charting the course for health care in Texas and may not always champion the incorporation of supportive and palliative care into their hospitals and health care systems. The Council, HHSC, THA, TMA, TNA, NASW, TAPA, SWHPN, and other stakeholders should collaborate to develop training/information materials designed to educate hospital and health system boards of directors and other leaders on the positive impacts of providing supportive and palliative care within their hospitals and networks.

#### **Recommendation IV: Promote the Highest Standards for Quality**

As the availability of palliative care services expands across Texas, the Legislature, HHSC, and industry groups must ensure that providers meet the highest standards for quality and avoid conflicts of interest. The availability of Board Certification or “added qualifications” in Palliative Care for physicians, APPs, nurses, social workers, and chaplains, as well as Joint Commission Certification for hospital based SPC programs or hospice programs should remind all that robust policies, practices, and quality standards designed to “foster the establishment, maintenance, and operation of patient centered, family focused” supportive and palliative care already exist. We recommend that both hospice and SPC providers participate in one or more of the National Quality Forum Palliative\_Care and End-of-Life Quality Measures available at [http://www.qualityforum.org/Topics/Palliative\\_Care\\_and\\_End-of-Life\\_Care.aspx](http://www.qualityforum.org/Topics/Palliative_Care_and_End-of-Life_Care.aspx). Moreover, HHSC, hospice and SPC providers, and other stakeholders should collaborate to develop a palliative and hospice score card for Texas to further promote quality and transparency in the industry.

HHSC should support efforts to improve quality measurement in palliative and hospice care by making educational resources available for each quality measure, and the Legislature should explore avenues for encouraging quality work through regulatory, licensing, and/or financial incentives via Medicaid.

In addition, a small number of Texas health care systems have currently adopted palliative care quality improvement initiatives as part of a Delivery System Reform Incentive Payment (DSRIP) project through the state's 1115 transformation waiver. The state should evaluate these projects and identify performance measures which show the greatest potential for positive change.

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Promoter(a) or Community Health Worker Training and Certification Program for more information, [http://dshs.texas.gov/mch/chw/Community-Health-Workers\\_Program.aspx](http://dshs.texas.gov/mch/chw/Community-Health-Workers_Program.aspx).

## Recommendation V: Provide Model Policies and Protocols for SPC Programs

HHSC and other industry stakeholders should partner to develop and promote effective technical assistance for hospitals seeking to establish or enhance their supportive and palliative care programs and for professionals seeking SPC related certification. This technical assistance could take the form of a web based library of model Texas policies, practices, and protocols related to supportive and palliative care developed by HHSC, the Council, THA, TMA, TNA, NASW, TAPA, SWHPN, and other stakeholders. We recommend that HHSC make available the 2013 National Consensus Guidelines for Quality Palliative Care<sup>36</sup> and that HHSC solicit copies of policies, procedures, and protocols from Texas providers of SPC services who have already achieved Joint Commission certification for the purpose of sharing these with other Texas facilities seeking to develop and/or maintain SPC services.

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<sup>36</sup> For background see: <http://www.nationalconsensusproject.org>.



## 5. Consensus Statement on Palliative Care Practices and Protocols

H.B. 1874, the Council's enabling legislation, contains several direct questions dealing with policies, practices, and protocols concerning patients' rights to information about palliative care. These questions have been slightly reframed for readability and our answers follow each question. The Council recommends no changes to state law in response to the questions; but offers guidance for best practices for SPC programs across the state.

1. May a palliative care team member introduce palliative care options to a patient without the consent of the patient's attending physician?
  - a. Hospitals have an ethical responsibility to make generic information about supportive and palliative care services available to all patients on admission, as well as when requested by a patient or family member. In the setting of serious illness, a patient's nurse, chaplain, or social worker has a responsibility to inquire of the primary treating provider whether an SPC consult might be appropriate. Furthermore, a nurse, chaplain, or social worker should be able to ask for a chart review (not a consult) by a palliative medicine professional or interdisciplinary team to determine if in the judgment of the professional or team, a consult might benefit the patient/family. These practices are long standing in institutions with leading SPC services. However, SPC consultation should be treated like any other medical consultation, and therefore a member of a SPC team should not discuss palliative care options with a patient unless there is a primary clinician or practitioner order for consultation or a patient or family request for consultation. Furthermore, when a patient or family directly requests an SPC consult, the consultant should communicate directly with the treating clinician or practitioner before interacting with the patient unless the reason for the consult is a symptom crisis. Even then, the palliative care professional should notify the primary clinician or practitioner as soon as practical.
2. What practices and protocols should be followed for discussions between a palliative care team member and a patient on life-sustaining treatment?
  - a. There are courses, lectures, articles, and books on this topic, and we will only provide a brief outline in our response. We note that many patients on life-sustaining treatment are not able to communicate, and discussions must be held with the patient's family or other surrogate. However, whether speaking directly with a patient or a family member/surrogate, the palliative care professional should follow a basic five-step approach including:
    - i. Introduce the SPC professional(s) name and role on the SPC team (i.e. physician, nurse or advanced practiced professional, chaplain, social worker, child life specialist, etc.), describe the nature of SPC services, and obtain permission to proceed from the patient/family/surrogate.

- ii. Determine what the patient or family has already learned and/or believes about their diagnosis, treatment options (including palliative options), and prognosis not only for survival but for other outcomes one might prognosticate about.
    - iii. Share information about the diagnosis, treatment options, and prognosis, and if there is bad news to be shared, do so only with further permission from the patient/family/surrogate.
    - iv. Determine patient/family/surrogate understanding of the information shared.
    - v. Make recommendations for next steps including follow up and obtain permission from the patient/family/surrogate for those next steps.
  - b. A key concept is permission, and, as a general rule, palliative care professionals and other professionals should avoid forcing a serious illness discussion that a patient, family, or surrogate does not wish to have.
3. What practices and protocols should be followed for discussions between a palliative care team member and a patient in regards to advance directives?
- a. Again, there are courses, lectures, articles, and books on this topic, and we will only provide brief guiding concepts in our response. We also note that asking patients/families/surrogates about the presence or absence of advance directives and offering information about and the option of completing one or more advance directives is required by the Patient Self Determination Act on admission to the hospital for all patients. Thus, advance directive discussions are not only in the purview of supportive and palliative care professionals but in the purview of all professionals serving hospitalized patients.
  - b. When it comes to SPC professionals, as with discussions about life sustaining treatment, a key concept is permission from the patient/family/surrogate to have a goals of care discussion followed by discussion of advance directives. No permission should mean no discussion because the primary reason for advance care planning is to preserve the patient's voice in the setting of terminal or irreversible illness at a time in the future when the patient is so ill he or she can no longer directly communicate.
  - c. With rare exceptions, goals of care and advance directive discussions with patients should be avoided until a patient's symptoms are under reasonable control to the patient's satisfaction.
  - d. SPC professionals typically see the sickest 5 to 10 percent of hospitalized patients and must remain aware at all times of the emotional burdens of such serious illness.
  - e. As explained above, SPC is distinct from Hospice, and SPC patients may continue aggressive medical interventions. Thus, SPC professionals must not assume that goals of care discussions will necessarily lead to limitations on life sustaining treatments but instead may lead to aggressive treatments. Whether the patient's preference is for limited, intermediate, or the most intense treatments, the patient's preferences should be clearly documented.
  - f. If the patient agrees to have a goals of care and advance directives discussion, we recommend a focus on living wills first, to be followed by creation of a medical

power of attorney, if desired, by the patient. Our rationale for this recommendation is as follows:

- i. Advance directives generally allow a more accurate expression of patient preferences if terminally or irreversibly ill and unable to communicate. This is especially true of modern digital advance directives allowing persons more flexibility and ease of change about treatment preferences, including video recording about preferences as well as easy storage and retrieval. Such directives are usable under Texas law since the Legislature approved digital signatures on advance directives.
- ii. The most recent study comparing the impact of physician/patient discussions, living wills, and medical power of attorney documents reveals that a physician/patient goals of care discussion reduces non-beneficial treatments near the end of life by a factor of almost two, and having a living will does so by a factor of 2.5, but when the medical power of attorney is the only directive, non-beneficial treatments are not reduced.<sup>37</sup> Non-beneficial treatments are associated with increased suffering of patient and family, but also increased costs for all.
- iii. When a medical power of attorney is desired, it should ideally be completed in conjunction with a living will. In matched pair studies, persons holding a medical power of attorney fail to accurately predict patient preferences in at least one-third of circumstances.<sup>38</sup> Our experience suggests this predictive inaccuracy is lessened if there is a written living will.
- iv. When a medical power of attorney is called upon to bear the emotional burden and moral responsibility of speaking for the patient, health care providers and facilities should be aware that the emotional decision making burden on the medical power of attorney is significant and may persist for years.<sup>39</sup> Therefore, emotional support should be provided to the medical power of attorney not only at the time of decision making but at future times as well. We recommend that facilities in which patients die offer bereavement support to surviving family members with special attention to those who carried the burden of decision making – with or without a medical power of attorney.

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<sup>37</sup> Amol K, Wright AA, Nicholas LH. *JAMA Oncol*. Published online July 09, 2015. doi:10.1001/jamaoncol.2015.1976).

<sup>38</sup> Shalowitz DI, Garret-Mayer E, Wendler D. *Arch Intern Med*. 2006; 166:493-497.

<sup>39</sup> Wendler D, Rid A. *Annals of Internal Medicine*, 2011; 154(5): 336-346.

4. What practices and protocols on informed consent and disclosure requirements for palliative care services should be followed?
  - a. As noted above, SPC is a board certified specialty just as is cardiology, surgery, or the myriad other specialties of modern medicine. Patients/families/surrogates should be offered palliative care services but must not be forced to accept those services any more than they should be forced to accept a cardiology consult.
  - b. Just as there are no specific consent documents for a cardiology consultation, so too there are no specific consent documents for a supportive and palliative care consult (or for that matter a hospice consult).

## 6. Guidance on the Palliative Care Education Program

In addition to assessing barriers to patient and family focused palliative care and recommending policy changes to address those barriers, H.B. 1874 charges the Council to advise HHSC on the operation of an education and information program for patients, families, and professionals. In this regard, the Council intends to leverage the full range of its expertise to support two program initiatives, a palliative care information website and a continuing education program. A description of each project and a summary of project plans approved by the Council is provided below.

### Palliative Care Information Website

The Council will take on key responsibilities for governing the palliative care information website authorized by H.B. 1874, in particular by routinely vetting and recommending specific content to be posted to the site. This quality control function performed by leading professionals in the field in conjunction with regular opportunities for public comment will ensure that information posted by HHSC into the public domain meets the highest standards and reflects a consensus view among interdisciplinary palliative care professionals in Texas.

The website will address many tasks that have been set by the recommendations of the Council, including but not limited to:

- Defining and promoting supportive and palliative care
- Directing the public to evidenced based, non-commercial patient friendly websites explaining the benefits of supportive and palliative care
- Hosting a directory for patients and families of Joint Commission certified SPC programs, Joint Commission certified hospice programs, American Board of Medical Specialties hospice and palliative care certified physicians, and hospice and palliative care educated/certified APPs in Texas
- Connecting to work being done by other stakeholders to create a “library” of Texas hospital policies, procedures, and protocols related to supportive and palliative care
- Sharing guidelines for quality palliative care and other technical assistance resources

The website will be hosted by HHSC and be consistent with other HHSC websites in terms of look and layout. It will include the following elements:

- Links to external resources regarding palliative care
- Links to continuing education opportunities for health care providers
- Information about palliative care delivery in the home, primary, secondary, and tertiary environments
- Consumer educational materials regarding palliative care, including hospice care

The Council will support governance for the website to ensure that the website provides the most accurate and up-to-date information for evidence based practices. Although the final

determination on all content belongs to HHSC, the Council will assess all material and links included on the site and, when appropriate, offer a vote of approval. A link or other material must receive a two-thirds majority approval from a quorum of the Council to earn a recommendation to HHSC. The Council will also play an ongoing role in assessing the effectiveness of the website and will recommend changes when necessary.

## **Continuing Education Program**

The Council plans to contribute directly to furthering continuing education (CE) related to palliative care in Texas. Initially, the Council's work in this area will focus on improving skills and knowledge among a wide range of practitioners by identifying and publicizing existing palliative care CE opportunities, identifying speakers to appear at events across the state, and periodically hosting its own educational events (in conjunction with the Council's quarterly meetings). The Council will also explore options to create, maintain, and host enduring educational materials on the Palliative Care Information Website or to share content for partners to administer and host.

The Council's main objective will be to support stakeholder CE initiatives in palliative care. The Council endorses the idea that the Palliative Care Information Website will serve as a hub for directing professionals to high quality trainings and educational events. HHSC program staff should also work with the Council to develop and maintain a master list of professional speakers (including Council members) and act as a liaison to facilitate appearances by these speakers at seminars, conferences, and other events hosted by program partners across the state.

In addition to supporting and promoting the work of others, the Council intends to conduct an annual, single day symposium led by the interdisciplinary palliative care professionals represented on the Council. The symposium would have the following elements:

1. It would be scheduled in conjunction with a short Council meeting to take advantage of Council members' travel to Austin; however, the CE event would be wholly separate from the Council meeting. The seminar would include contributions from Council members and invited speakers.
2. The symposium would be widely advertised and available live online through webinar and video to reach as many Texas professionals as possible. Topics could range from generalist information to profession-specific training.
3. Each seminar would allow for a question and answer portion at the end.
4. HHSC staff supporting the Council would be responsible for ensuring that administrative requirements are followed and documented so that attendees are awarded appropriate CE credits.

5. Participants would have the opportunity to submit evaluations of each event. These evaluations will provide a feedback method to grow and improve the CE program.
  
6. All sessions would be archived and made available for online viewing whenever possible.

In theory, archived Council educational events could be developed into enduring material from which CE credits could be awarded. Enduring material consists of any activity that is printed or recorded and does not have a specific time or location designated for participation. Enduring material that results in CE credit must include an assessment component and be accompanied by a reliable administrative process for awarding the credit. HHSC and the Council are exploring technological, cost, and legal logistics to inform how the CE credits from enduring material generated from its symposium could be developed, certified, and administered.

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## 7. Conclusion

The Texas Legislature established the Palliative Care Interdisciplinary Advisory Council to provide objective evaluation and consensus recommendations to increase the availability of patient and family focused palliative care in Texas and to assist HHSC with the establishment and operation of an ongoing palliative care information and education program. Over the course of 2016, the Council has pursued these charges in full public view and in partnership with the many stakeholders committed to improving palliative care services in Texas. The Council's assessment confirms the Legislature's belief that significant and broad improvements in palliative care are possible in Texas and such improvements will contribute to better outcomes, higher satisfaction, and smarter spending for patients, families, and payers. The Council hopes that this initial report can serve as a catalyst for a sustained quality improvement effort and looks forward to continuing its work to make Texas the national leader for providing appropriate, compassionate, and high quality palliative care to patients and families at any age and at any stage of serious illness.

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## 8. Abbreviations and Acronyms

<b>Acronym</b>	<b>Full Name</b>
ABMS	American Board of Medical Specialties
AD	Advance Directives
AHA	American Hospital Association
APRN	Advanced Practice Registered Nurse
APP	Advanced Practice Professionals
CAPC	Center to Advance Palliative Care
CE	Continuing Education
CHAP	Community Health Accreditation Partner
DADS	Department of Aging and Disability Services
DFPS	Department of Family and Protective Services
DPOA	Durable Power of Attorney
DNR/DNI	In Hospital Do Not Resuscitate/Do Not Intubate
DSHS	Department of State Health Services
DSRIP	Delivery System Reform Incentive Payment
H.B.	House Bill
HC	Hospice Care
HHS	Health and Human Services
HHSC	Health and Human Services Commission
ICU	Intensive Care Unit
MPOA	Medical Power of Attorney
NASW	National Association of Social Workers
OOHDNR	Texas Out of Hospital Do Not Resuscitate
PA	Physician Assistant
PC	Palliative Care
PCIAC	Palliative Care Interdisciplinary Advisory Council
PHR	Public Health Region
PTSD	Post-Traumatic Stress Disorder
SPC	Supportive and Palliative Care
STEEEP	Safe, Timely, Effective, Efficient, Equitable, and Patient-Centered

<b>Acronym</b>	<b>Full Name</b>
SWHPN	Social Work Hospice and Palliative Care Network
TAPA	Texas Academy of Physician Assistants
THA	Texas Hospital Association
TMA	Texas Medical Association
TNA	Texas Nurses Association

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## 10. Appendices

### Appendix A: List of Core Competencies and/or Values by Profession

#### Continuing Medical Education Core Competencies

- Patient care
- Medical knowledge
- Practice-based learning and improvement
- Interpersonal and communication skills
- Professionalism
- System-based practice

#### Institute of Medicine Core Competencies

- Provide patient-centered care
- Work in interdisciplinary teams
- Employ evidence-based practice
- Apply quality improvement
- Utilize informatics

#### National Association of Social Workers Core Values

- Service
- Social justice
- Dignity and worth of every person
- Importance of human relationships
- Integrity
- Competence

#### American Nurses Association Nursing Code of Ethics

"Compassion and respect for inherent dignity, worth, and uniqueness of every individual unrestricted by considerations of social or economic status, personal attributes, or the nature of health problems. Professional nursing is collaborative, individualized, and promotes healing in a way that builds relationships through caring."

## Appendix B: List of Online Education Materials

A wide variety of continuing education materials are available online via webinars and self-paced courses to educate advanced practice professionals about palliative care. While not exhaustive, the table below lists current webinars and online courses hosted by leading organizations and educational institutions. This list is provided for informational purposes only and its inclusion in this report does not imply the endorsement of the Council, of any particular member of the Council, or of the organizations represented by the Council.

Organizations include:

- American Academy of Hospice and Palliative Medicine (AAHPM)
- California State University Institute for Palliative Care (CSU-IPC)
- Center to Advance Palliative Care (CAPC)
- Metropolitan Jewish Health System Institute for Innovation in Palliative Care (MJHS-IIPC)
- National Hospice and Palliative Care Organization (NHPCO)
- Texas Academy of Palliative Medicine (TAPM)
- Texas and New Mexico Hospice Organization (TNMHO)

Topic	Organization
AAHPM Primer of Palliative Care	AAHPM
Advance Care Planning Conversations	CAPC
Advanced Conversations and Opioid Side Effects	CAPC
Advanced Palliative Care Chaplaincy Specialty Certificate	AAHPM
Advanced Practice RN Certificate in Palliative Care	AAHPM
Advances in Pain and Symptom Management	NHPCO
An Understanding of Ritual at End of Life	MJHS-IIPC
Anxiety, Agitation, and Restlessness: Oh My!	NHPCO
Applying Motivational Interviewing Techniques and Interventions in Palliative Care	CSU-IPC
Aromatherapy in Palliative Care	CSU-IPC
Assessing Risk for Opioid Substance Use Disorder	CAPC



<b>Topic</b>	<b>Organization</b>
Assessment and Management of Fatigue in Medical Illness	MJHS-IIPC
Audits, Fraud and Abuse: Steering Clear of the “Dark Side”	NHPCO
Beyond Measuring: Improving through PIPs	NHPCO
Breakthrough Pain: Its Consensus and Controversies	MJHS-IIPC
Burnout: Effective Interventions for Hospice and Palliative Care Clinicians	AAHPM
Certified Hospice and Palliative Nurse (CHPN) Exam Preparation	AAHPM
Clarifying Goals of Care	CAPC
Comprehensive Assessment and Plan of Care: Best Team Practices	NHPCO
Comprehensive Pain Assessment	CAPC
Continuum of Care: Understanding the Regulatory Requirements	NHPCO
Converting from Short-Acting to Long-Acting Opioids	CAPC
Critical Palliative Care Skills for Social Workers	AAHPM
Culturally Competent Palliative Care of Latinos	CSU-IPC
Debility, Failure to Thrive, and Other Diagnosis Reporting Dilemmas	AAHPM
Delivering Serious News	CAPC
Do the Right Thing: Resolving Ethical Challenges	NHPCO
Effective Advance Care Planning: Skill Building for Entire Organization	CSU-IPC
Eligibility: Prognosis, Relatedness: Ensuring Compliant Practice	NHPCO
Everything You Wanted to Know about Elections, Terminations and Revocations But Were Afraid to Ask	NHPCO
Evidence-Based Practices in the Management of Common Symptoms: Hiccup, Cough, and Itch	MJHS-IIPC
Facilitating Meaningful Life Review	NHPCO
Family Caregivers in Hospice and Palliative Care: Maximizing Support and Minimizing Burden	MJHS-IIPC

<b>Topic</b>	<b>Organization</b>
Five Things Physicians and Patients Should Question in HPM: Communicating AAHPM's Choosing Wisely® Recommendations to Patients and the Public	AAHPM
Following Patients Where They Travel: A Community Model of Care	CAPC
“Futility” and Goals in the Illness Trajectory: Setting Boundaries	MJHS-IIPC
HMD PREP	AAHPM
Hospice Medical Director Manual	AAHPM
HPM FAST modules	AAHPM
HPM PASS	AAHPM
“I Dunno...” – Helping Teens Cope with Grief	NHPCO
Is It Spiritual Suffering? How to Know, What to Do	NHPCO
Is Your Team Culturally Aware and Sensitive? Are You?	NHPCO
Is Yours a Good Team? Going from Good to Great	NHPCO
LGBT Elders: Implications for Hospice and Palliative Care Providers	NHPCO
Managing Pain in Patients at Risk for Substance Use Disorder	CAPC
Matching the Drug Class to the Pain	CAPC
Monitoring for Opioid Efficacy, Side Effects and Substance Use Disorder	CAPC
On the Edge of a Cliff? Coping with Stress and Compassion Fatigue	NHPCO
Oncologic Emergencies for the Palliative Care Specialist	MJHS-IIPC
Opioid Trials: Determining Design, Efficacy and Safety	CAPC
Pain Management: Putting it All Together	CAPC
Painting a Clear Picture: Excellent Documentation Practices	NHPCO
Palliative Care Chaplaincy Specialty Certificate	AAHPM
Palliative Care Competency Framework for Chaplains	AAHPM
Palliative Care for Care Managers	AAHPM

<b>Topic</b>	<b>Organization</b>
Palliative Care in Parkinson's Disease and Other Neurodegenerative Diseases	MJHS-IIPC
Palliative Care Measurement Made Easy	CAPC
Partnering With Commercial and Medicare Advantage Plans	CAPC
Patient Factors that Influence Prescribing Decisions	CAPC
Prescribing an Opioid	CAPC
Prescribing Practice and Opioid Conversions	CAPC
Prescribing Short-Acting Opioids: Four Case Studies	CAPC
RN Certificate in Palliative Care	AAHPM
Special Populations and Patient-Controlled Analgesia	CAPC
Supporting the Family Caregiver: The Burden of Serious Illness	CAPC
Texas New Mexico Hospice Organization Annual Conference	TNMHO
Tackling Adverse Events: Don't Let Them Take You Down	NHPCO
The Business Case for Palliative Care	CSU-IPC
The Meridian Care Journey Program: A Survival Guide to Home-Based Palliative Care	CAPC
Thrombosis and Bleeding: Managing Common Problems in Advanced Illness	MJHS-IIPC
Top Ten Pharmaco Mistakes at End of Life	AAHPM
UNIPAC Self Study Series	AAHPM
What Does the Palliative Care Specialist Need to Know About Prescription Drug Abuse?	MJHS-IIPC
What Every Nurse Needs to Know About Palliative Care	AAHPM

*Examples of National Conferences:*

- National Hospice and Palliative Care Organization has a virtual conference Aug. 9-11, 2016
- International Conference on Aging and Gerontology, Aug. 8-9, 2016, Las Vegas
- International Conference on Geriatric Medicine and Gerontology, Nov. 14-16, 2016 Atlanta

- Palliative Care in Oncology Symposium, Sept. 2016, San Francisco
- American Academy of Hospice and Palliative Care Summer Institute, Jul. 2016, Pittsburgh

*Institutions in Texas with Palliative Medicine Services with Fellowship Programs:*

Texas Tech University, Lubbock

<http://www.ttuhscc.edu/som/fammed/residents/palliativecarefellowship.aspx>

University of Texas Health Science Center at Houston

<https://med.uth.edu/internalmedicine/divisions/geriatric-palliative-medicine/>

University of Texas Health Science Center at San Antonio

<http://medicine.uthscsa.edu/geriatrics>

University of Texas M.D. Anderson Cancer Center, Houston

<https://www.mdanderson.org/education-training/clinical-research-training/graduate-medical-education/residencies-fellowships/hospice-palliative-medicine.html>

University of Texas Southwestern Medical Center- Dallas

<http://www.utsouthwestern.edu/education/medical-school/departments/internal-medicine/divisions/general-internal-medicine/palliative>

*A Note about Profession Inclusivity*

Please note within these lists, each organization or institution specifies which professionals may receive accreditation, and are often provided exclusively to physicians, physician assistants, nurses, social workers, counselors, and pharmacists. Professionals not included in most categories include certified health education specialists and registered sanitarians, though these groups may petition for credit.

## **Appendix C: Council Member Letter**

All Council members were invited, at their discretion, to submit a personal comment letter to be included as an appendix. Please note comment letters represent only the personal views of the submitter. Consensus findings, recommendations, and guidance endorsed by the full Council can be found in Chapters 1 through 7 of this report.

The Council member listed below provided a comment letter for this report.

- Erin Perez, APRN, ANP-C, AGNP-C

## **Texas Palliative Interdisciplinary Advisory Council Personal Statement**

As a member of the Palliative Care Interdisciplinary Advisory Council, I have worked with my colleagues to identify some of the barriers to increasing access, education, and awareness of palliative health care services for Texans. One of those barriers is the inability of advanced practice providers (APPs) -- such as nurse practitioners and physician assistants -- to sign death certificates and Do Not Resuscitate (DNR/OOHDNR) orders for the hospice and palliative care patients who are under their care.

In Texas, APPs are allowed to serve as a patient's primary care provider and oftentimes are a hospice patient's attending provider of record. Despite this fact, under current Texas law, APPs are prohibited from signing the medical certification for any death certificate. APPs are also not permitted to sign the in-hospital and out-of-hospital DNR orders.

Having a 91 year old grandfather who is a WWII marine vet in Del Rio, a border town to Acuna, Mexico, his primary and my deceased grandmothers care has been provided by a physician assistant. Most of his specialists are in San Antonio, at least 3+ hours away.

When my grandfather needed to complete his advanced care planning (medical power of attorney, advanced directives with out of hospital DNR), he had to drive to San Antonio and talk to a handful of specialists, to find one willing to sign, as they were not the primary/attending to sign the OOHDNR. Unfortunately, we were not able to do all the legal documents medically appropriate at the same time. Fortunately, he did not have a code blue, and need the OOHDNR document in the wait period.

Particularly in the end stages of a patient's care, APPS are often the medical clinicians most familiar with the patient's condition and cause of death. Only allowing physicians to sign death certificate -medical certifications can lead to delays in: issuing death certificates, undo stress and hardship on the deceased's family and friends. This also places unnecessary burden on physicians required to sign death certificates for patients they never or rarely saw. I have experienced this issue as provider, and more personally, as a family member who went through the painful process of coordinating the end-of-life care of those I love.

When my grandmother was dying, there was great chaos and confusion in the medical team. In the small border town of Del Rio where she and my grandfather lived, there was no hospice and very few providers who had knowledge or experience with true evidenced based hospice symptom management. At one point during the process, I had to personally call the chief medical officer (CMO) of her facility to clarify the end-of-life care medication needs. Having your mother describe profound myoclonic jerking, uncontrolled pain and respiratory distress ("breathing like a freight train") as you are driving from San Antonio, after finishing your home hospice shift, is distressing and highly concerning to say the least.

At the same time we were struggling to attain quality of life at end of life by advocating for appropriate medications to ease her end of life symptom burden, I also had to comfort my

family and educate the medical team quickly on evidence based practice for a patient with hour's prognosis.

When I finally arrived from San Antonio to Del Rio to be with my grandmother during her final hours, I found her indeed still waiting, suffering unduly from tremendous pain, respiratory distress accompanied with severe myoclonic jerking. After making many more calls and waiting for hours, medication finally arrived to alleviate her symptoms under my unwavering requests and merciful pleas for medication from her providers and giving support and extensive coaching to the staff in the facility to administer the now prescribed interventions. But those hours of waiting were torment for my family, and no patient should have to endure what my grandmother endured that day.

I was able to provide adequate symptom management and hold death vigil at her bedside. This was a true multi-faceted end of life care crisis. Yes, after all those hours of waiting, medication finally alleviated her symptoms and my grandfather was able to see her resting comfortably. She eventually died in less than 24 hours. She died peacefully with myself, my mom and my grandfather at her side.

My grandmother did not get basic end of life care support in a timely matter. What would have become of her should my family and I had not been there to advocate on her behalf? Dignity and prudent medical attention for end of life care was grossly delayed.

After my grandmother died, our troubles were still not over. The next problem we faced was that my grandmother's physician assistant could not sign her death certificate. This further delayed insurance and funeral arrangements. I remember pulling over outside of D'Hanis and weeping ... How could my family, of all families, have to endure such travesties? We only have one chance for a peaceful and dignified death.

As an adult and geriatric nurse practitioner who has years of hospice and palliative care experience, my patients and I should not have to wonder: Who will sign the DNR? Who will sign the death certificate? How long will these delays cause undue stress and grief for the patient and family?

As a palliative provider, I am consulted by the attending, primary care clinician and/or specialist to help provide an extra layer of support to the patient and the family. I am charged with balancing comfort and function within the context of the patient centered goals of care. I am the one who is entrusted to serve the patient and family, walking the patient and family through these hard discussions, clarifying the disease process, plan of care, risk vs. benefits of medically appropriate treatment options, clarifying goals, wishes, advanced care planning (complex code status discussion, medical power of attorney, advanced directives), symptom management and prognosis.

As a registered nurse, I can pronounce the patient. As a nurse practitioner, I can diagnosis, interpret diagnostics, prescribe, and order treatments -- but my hands are tied for the in-hospital and out-of-hospital DNR, as well as the death certificate.

I am fortunate to have physician friends who are willing at times to sign these documents when needed. I provide the cause of death diagnosis and have them sign documents after I have discussed it with the patient and family. When this happens, families are puzzled about the delay and why they need to find a provider with whom they've had little or no contact to sign the DNR and death certificate.

Twenty-four states and the District of Columbia permit APPs like myself to sign death certificate- medical certifications. Many states have passed or are proposing similar legislation to allow APPs to sign DNR orders as well. I humbly recommend that the legislature consider the same legislative fix in Texas. Let Texans help Texans at their most vulnerable, intimate and sacred times.

This recommendation has the support of the members of this Council, who represent the many disciplines and health care professionals that make up the palliative care team. Such a move would come with no additional cost or burden to the system, but would have a significant impact on end-of-life care for the patients we serve every day.

Will Texas help me help not just my family but those I am entrusted to care for? I would ask humbly for the legislators to pass legislation to allow the APPs (PA and APRN) to sign the IN and OUT of hospital DNR and death certificate. Please do not let my family and other patient experiences happen to the one's you love and care for. Please do not let their experiences fall through the fragmented legislative cracks.

I am honored to work diligently among peers on this council. I am so appreciative of the council and legislator's time and consideration to help better patient and family needs at their most vulnerable time in Texas.

Best Regards,  
Erin

Erin Perez, APRN, ANP-C, AGNP-C  
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## **Appendix D: Stakeholder Letter**

Stakeholders were invited, at their discretion, to submit a personal comment letter to be included as an appendix. The stakeholder listed below provided a comment letter for this report.

- Ellen Martin, PhD, RN, CPHQ

The Texas Nurses Association commends the PCIAC on their work in developing this report and recommendations. We recognize the importance of palliative and supportive care and look forward to the opportunity to partner with other stakeholders in advancing palliative care in Texas and supporting the recommendations of this Council.

-Ellen Martin, PhD, RN, CPHQ  
Director of Practice  
Texas Nurses Association