

**FINAL  
REPORT**

PALLIATIVE CARE AND QUALITY OF LIFE  
TASKFORCE



January 15, 2018

## Introduction by Former U.S. Senate Majority Leader, Dr. Bill Frist



Senator William H. Frist, MD  
Former U.S. Senate Majority

As a heart and lung transplant surgeon, I have had many conversations with patients and families about illness, death, and dying. In listening, I found that it is quality of life that often matters most: being able to attend a graduation or be present at Christmas; spending more time with the grandkids; and more time in the comfort of their own home. No one ever asked me to spend more time in a hospital.

Unfortunately, in our current fee-for-service model, the focus is on either life-prolonging aggressive care (the “do everything always” approach), or simply ceasing any curative treatment and then transferring to hospice when patients have a life expectancy of less than six months.

For patients with chronic and advanced illnesses who may have many months or years still ahead of them, these two options often don’t meet their needs or wishes for better quality of life. Instead, patients find themselves cycling in and out of emergency rooms and hospitals, chaotically bouncing back and forth to doctors’ offices, and juggling a confusing array of medicines prescribed by different physicians. In fact, Americans today visit a doctor an average of 29 times<sup>[1]</sup> in their last 6 months of life, and roughly 80 percent<sup>[2]</sup> die in a hospital, nursing facility, or assisted living facility instead of in their homes – which is where 80 percent of people say they want to be at the end of life.

For individuals living with life-threatening illnesses like cancer, COPD, heart disease or kidney disease, their interactions with the health care system can be confusing, chaotic, and expensive. A recent Kaiser Family Foundation analysis<sup>[3]</sup> found that the average total Medicare per capita spending in 2014 was nearly four times higher for beneficiaries who died (\$34,529) than for those who lived the entire year (\$9,121). More care doesn’t always mean better care, or better outcomes, and at times can mean more stress and suffering for patients and the people who love them.

As our health care system begins its shift to value-based care, we have opened the door to a new approach that can more efficiently and effectively deliver care to patients with chronic and advanced illness with an emphasis on quality of life. Imagine care that places the patient at the center, with resources brought to them. They would receive 24/7 telephone support from skilled medical professionals, helping prevent an unwanted trip to the emergency room. In-home visits by providers to administer medications might avoid unwanted hospitalizations, allowing the patient to stay with their family. Discussions with a social worker would help suffering patients navigate the care system, reducing their stress and ensuring they can access community-based resources. This approach is palliative care.

Palliative care -- unlike hospice care wherein a person foregoes “curative care” and disease-focused treatments -- provides comprehensive care and treatment, care coordination across settings, and shared decision making for those living with chronic and advanced illnesses. Palliative care treats the mental, emotional, physical and spiritual needs of the patient with a team of caregivers that frequently includes a specialty trained palliative care physician, nurse or nurse practitioner, social worker, and chaplain. The team serves as an extra layer of clinical and emotional support to provide relief from the symptoms, pain, and stress of serious illness by working with individuals and their families to ensure their care needs and goals are accurately identified and systematically addressed. This care can and should happen in a variety of care settings: hospital, nursing facility, or right where a patient lives.

Studies have shown the benefits of palliative care. A 2010 study published in the *New England Journal of Medicine* demonstrated that cancer patients receiving palliative care showed 58 percent less depression

and 39 percent less aggressive end-of-life care, and longer median survival times by several months.<sup>[4]</sup> Another seminal study found, in a randomized control trial, that those who received palliative care had 30 percent fewer emergency department visits, 28 percent fewer hospital admissions and two years' more life expectancy. Along with feeling better and living longer, these patients also cost thousands of dollars less over the course of their last year of life.<sup>[5]</sup>

I saw improved outcomes firsthand in the 1980s at Stanford and later at Vanderbilt when standing up the Multi-Organ Transplant Center. Palliative care was still in its infancy when we set up the first-of-their-kind, multidisciplinary care teams that managed each our severely ill heart transplant patients. We witnessed then how much better our patients fared if we together discussed their expectations and together outlined a holistic treatment plan that addressed all possible outcomes – including death.

My own personal experience with the team-based palliative model in transplantation led me in 2013 to create, with co-founder Brad Smith, Aspire Health. Aspire Health has grown to become the largest, non-hospice, community-based palliative care organization in the country, treating over 20,000 patients a day – with many of those patients right here in Tennessee. Most individuals don't know the word "palliative," so we describe ourselves as a "house call physician practice" available around the clock for persons with debilitating chronic or advanced illness. By moving the locus of care to the home, which is a central piece of palliative care, the patient is more comfortable and the care is more cost-effective. But our organization touches just a small fraction of those who could benefit from access to this model.

Across our state and country, there remain significant gaps in the availability of palliative care and a shortage of trained providers, particularly in rural areas. Rigid fee-for-service reimbursement systems make palliative care challenging to implement in the way that patients need it.

So it is a simple question: If this is the standard we found so valuable for patients with advanced chronic disease awaiting transplant at Vanderbilt, and if this is the care that succeeds from the perspective of patients, families, providers, and payers, why 30 years later is it not easily available to the millions of people with living with serious illnesses in communities near the best hospitals in the world, as well as those who far away from inpatient health centers?

The Tennessee General Assembly smartly established the Palliative Care and Quality of Life Task Force to address questions such as this. We stand at an inflection point where a more rational and successful system of care is possible. Palliative care meets the "triple aim" of better health, improved care and lower cost. The Task Force's key findings and recommendations ring true to me as a physician and policymaker focused on improving advanced illness care, and I urge the General Assembly to give them serious consideration and lend their strong support.



Senator William H. Frist, MD  
Former U.S. Senate Majority Leader (2002-2007)



## Acknowledgements

Thank you to the many people who assisted in the development of this report and a heartfelt thank you to the members of the Palliative Care and Quality of Life Task Force who shared their expertise. It is hoped that the implementation of the recommendations contained in this report will result in increased access to palliative care for all Tennesseans.

Specific thanks go to the following individuals:

Governor Bill Haslam and the Tennessee General Assembly who created by the Palliative Care and Quality of Life Task Force as a result of Chapter 420 of the Public Acts of 2017

Senator Joey Hensley

Representative Sabi Kumar

American Cancer Society Cancer Action Network of Tennessee

Lynn Williams, American Cancer Society Cancer Action Network of Tennessee

Jessica Brooks, American Cancer Society Cancer Action Network of Tennessee

Members of the Task Force

Public attendees of Task Force meetings

The individuals that presented at the Task Force Meetings

Mike Dietrich, Tennessee Hospital Association and Tennessee Hospice Organization

Marian Grant, Coalition to Transform Advanced Care

Kate Lach, Aspire Health

Melinda Bailes, Vanderbilt University Medical Center

## **Members of the Palliative Care and Quality of Life Task Force**

Senator Joey Hensley

Representative Sabi Kumar

Clay Jackson, Methodist Hospice & Palliative Care

Faye Hollowell, Patient Care Advocate

Thomas Jaselskis, Wilson County Health Department

Andrew Lasher, Aspire Health

David Wooten, Covenant Health

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Melissa Cooper, Mountain States Health Alliance

Tracy Hills, Monroe Carrell Jr. Children's Hospital at Vanderbilt

Mohana Karlekar, Vanderbilt University Medical Center

Jim Shulman, Tennessee Commission on Aging and Disability

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## Executive Summary

Pursuant to legislation passed in 2017 by the Tennessee General Assembly, from September 2017 through December 2017, a diverse group of representatives from Tennessee's leading health care and community organizations, advocacy and professional associations, and consumers, met to discuss Tennessee's palliative care needs.

In addition to creating this report, which provides recommendations on how Tennessee can address the palliative care needs of its residents, Task Force members and members of the public demonstrated a commitment to ensuring equitable access to palliative care for all Tennesseans.

With a defined Task Force goal "to develop recommendations to address problems associated with the availability of palliative care," the Task Force developed recommendations in key categories: Providers, Patients, and Systematic/Structural. Together, the recommendations provide a framework for increasing access to palliative care across the state.

Although Tennesseans' values and opinions about care for serious illnesses including palliative care and/or end-of-life care will inevitably vary by person, the task force recognizes the importance of increasing access and accurate dissemination of information so that individual care decisions can be made.

## **Palliative Care and Quality of Life Task Force History and Background**

The Palliative Care and Quality of Life Task Force was created by the Tennessee General Assembly as a result of Chapter 420 of the Public Acts of 2017. Pursuant to the language of that Public Chapter, the Task Force was to:

- (1) Assess the current status of palliative care in this state;
- (2) Examine the existing barriers, services, and resources addressing the needs of individuals who could benefit from palliative care; and
- (3) Develop recommendations to address problems associated with the availability of palliative care.

Upon the completion of its study, the Task Force was to make recommendations and submit findings to the governor and the general assembly by January 15, 2018.

The Tennessee Commission on Aging and Disability (TCAD) was legislatively assigned administrative responsibility for the committee. Membership in the Task Force was defined in the formation legislation. Senator Joey Hensley and Representative Sabi Kumar were the designated representatives from the Senate and the House. Jim Shulman, the Executive Director of the Tennessee Commission on Aging and Disability, also served. The remaining members of the Task Force were made up of representatives from the field of palliative care.

- Clay Jackson, Methodist Hospice & Palliative Care
- Faye Hollowell, Patient Care Advocate
- Thomas Jaselskis, Wilson County Health Department
- Andrew Lasher, Aspire Health
- David Wooten, Covenant Health
- Karen Hyden, Compassus
- Melissa Cooper, Mountain States Health Alliance
- Tracy Hills, Monroe Carrell Jr. Children's Hospital at Vanderbilt
- Mohana Karlekar, Vanderbilt University Medical Center

After holding three meetings in 2017, the Task Force reviewed a total of five proposed recommendations. After discussion, the Task Force voted unanimously to include all five recommendations in its Final Report.

## Summary of the Legislative Palliative Care and Quality of Life Task Force Meetings

### **September 7th, 2017**

The Task Force met a total of three times during 2017 with the initial meeting taking place on September 7th, 2017. The primary purpose of the first meeting was to appoint a chairman and review the purpose and legislative intent of this Task Force. Mr. Shulman made the motion that Senator Hensley be appointed as Chairman of the Task Force and the members unanimously agreed. Senator Hensley made the motion that Representative Kumar be appointed Vice Chairman of the Task Force and the members unanimously agreed.

Ms. Lynn Williams, the Tennessee Government Relations Director for the American Cancer Society Cancer Action Network (ACS CAN), reviewed legislative history of palliative care and answered questions regarding the Tennessee Cancer Coalition. ACS CAN is an advocate for improving quality of life for cancer patients and cancer survivors.

Chairman Hensley reviewed the purpose of the Task Force and then led a discussion of expectations and concepts with a focus on existing patient and physician barriers.

Chairman Hensley invited audience members to provide insights on palliative care. The Chief Medical Officer (CMO) of Hospice of Chattanooga, Dr. Greg Phelps, gave a brief overview of the Palliative Care and Geriatrics rotation at UT Medical School. When discussing palliative care, he put focus on comfort, coordination, and communication. The President and Chief Executive Officer (CEO) of Alive Hospice, Ms. Anna-Gene O'Neal, gave a brief overview of her organization's mission and requested that the Task Force identify where hospice care could ally with palliative care and share resources.

### **Key Findings from September 7th, 2017 Meeting**

- Patient's point of view is crucial to a more refined and further disseminated definition of palliative care.
- Effective palliative care requires multidisciplinary care team with a patient focused plan.
- Education for professionals and public is key component to advancing palliative care.
- There is a need to research structure including funding, reimbursement models, delivery models, and use of telemedicine.
- Explore federal and state activity in palliative care including how states address barriers.

## **October 13<sup>th</sup>, 2017**

The second meeting of the Task Force took place on October 13, 2017 with a focus on state-by-state palliative care initiatives and taskforces, and the geographic distribution of palliative care providers throughout the state of Tennessee. After the meeting was called to order by Chairman Hensley, the staff from TCAD presented a brief summary of palliative care initiatives in other states. This included an overview of legislation passed in other states as a product of palliative care councils (Appendix A).

The next presentation by TCAD staff provided an overview of palliative care provider locations in Tennessee. Data presented included maps of board certified physicians, hospitals providing palliative care, and recent graduates from Tennessee's two palliative care graduate medical education (GME) programs located in Nashville and Memphis (Appendix B). It was found that there were geographic disparities between the various regions within Tennessee. Most notably, a gap exists for providers in rural areas of the State. TCAD staff, in making the presentation, also emphasized the lack of centralized data or tracking for Tennessee's Palliative Care Taskforce, including mid-level providers (physician assistants, nurse practitioners) and allied health professionals (social workers, dietitians, etc.). Taskforce members stated that clinicians typically know fellow palliative care physicians through professional networks rather than through a formalized database. This could become a barrier for individuals in communities with a lack of resources or professional network. The integration of physician networks with formalized order to maximize patient connection, Tennessee's major hospitals could be linked to providers that complete GME in palliative care specialties. Retention and dissemination of these providers throughout the state is crucial to the future of palliative care's influence on patients in rural and urban areas of Tennessee.

Mr. Mike Dietrich, a representative of the Tennessee Hospital Association (THA) and Tennessee Hospice Organization (THO), then addressed to Task Force; he indicated that there was potential for partnership with the Task Force in order for final recommendations and future efforts to affect hospitals and communities. This partnership would help disseminate information and resources related to palliative care through care networks around the State. The presenter also mentioned the need for more data on cost-avoidance through palliative medicine and research in alternative payment models.

An additional presenter, Ms. Marian Grant of the Coalition for Transform Advanced Care (C-TAC), discussed palliative care initiatives from a national perspective. The presenter discussed existing demonstration projects as well as evaluation of potential alternative payment models. The presenter also emphasized the importance of tracking results and initiatives to better inform policy and evaluate palliative care outcomes.

Ms. Jessica Brooks, a representative of the ACS CAN gave the final presentation on a palliative care website in development by the Tennessee Cancer Coalition.

### **Key Findings from October 13, 2017 Meeting**

- Important to build upon the successes of taskforces and councils of other states, so as to not duplicate work with the understanding that Tennessee is its own unique state.
- There are clear geographic disparities in regards to palliative care access.

- The clinician and patient need is present for a real-time, online registry of the palliative care workforce (including physicians, nurses, hospital programs, and allied health)
- Important to consider alternative payment model for palliative medicine because this type of care improves patient satisfaction and saves money overall.
- Important to consider: “Right care, right patient, right time”
- Consider retention strategies for GME graduates in order to increase palliative care workforce within Tennessee and evenly spread providers throughout geographic regions.

### **December 8th, 2017**

The Palliative Care and Quality of Life Task Force convened for the third time on December 8th, 2017 with the focus on patient, family, and social perspective. The meeting began with the Task Force’s patient advocate, Ms. Faye Hollowell, who recounted a family member’s battle with cancer and stated the potential benefit her family could have experienced through palliative care. She asserted the importance of initiating conversations about “living last days well” in light of a major shortage of patient advocates. The shortage of advocates and providers further increases the need for training of patients and caregivers. Ms. Hollowell introduced various methods by which individuals can begin difficult conversations with their families. Although palliative care by definition is not always end-of-life care, it is crucial for the patient, the patient’s caregivers, and provider teams to understand the patient’s wishes. Task force members indicated that there was a need for community based tools to encourage these discussions among patients and their families. Potential placement of discussion tools in congregate living settings, faith-based communities, waiting rooms, or dialysis clinics was also discussed. Task force members also asserted the need to utilize these conversations to create official legal documents, such as Advanced Directives and POST Forms.

The second presenter, Kate Lach, Director of Social Work with Aspire Health, reviewed the Aspire Health model with a focus on the social worker’s role. She stated that this model is not specifically focused on Value-Based Insurance Design; however, she mentioned Aspire submitted a potential advanced care model to the Centers for Medicare and Medicaid (CMS) and will reconvene with the agency in March 2018 to discuss.

The final presenter, Melinda Bailes, is both an inpatient and outpatient palliative care social worker from Vanderbilt University Medical Center. The presenter helped begin the Vanderbilt Palliative Care program in the early 2000s. She stated that effective interdisciplinary palliative care teams produce: greater patient satisfaction, increased Advanced Directives, decreased health care costs and decreased intensive care unit admissions. She also emphasized the importance of colloquial communication with patients and their families. Despite palliative care’s strong outcomes, the presenter also noted the shortage of palliative care providers in the community, particularly in rural areas.

The meeting concluded with a review of past meetings and a list of potential recommendations. By verbal consensus, task force members decided to keep recommendations as drafted with the understanding that the report will be sent electronically for review prior to submission. Each

individual task force member will review and approve before submission to legislature on January 15<sup>th</sup>, 2018

**Key Findings from December 8, 2017 Meeting**

- There is a need for innovative ways to increase patient/family comfort with end-of-life discussions
- Physicians must understand the benefits of palliative care in both inpatient and outpatient care settings.
- Patient advocates need to be involved in care plans and assist in development of physician protocol on patient-centered, palliative care conversations.
- The interdisciplinary team plays a key role in both inpatient and outpatient palliative care settings.

## Palliative Care Overview

To many, the words “palliative care” brings to mind end of life care. And while all hospice care is palliative care, all palliative care is not hospice care. Instead, palliative care is a specialized medical approach that deals with focusing directly on a patient and their needs as they deal with life-threatening or life-limiting illness including chronic diseases. People can live for years with chronic diseases; palliative care is the practice of focusing on how to improve that patient’s quality of life while living with that disease.

### **What is Palliative Care?**

According to the World Health Organization, “Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.” Through this broad definition of palliative care, the Center to Advance Palliative Care (CAPC) adds that “Palliative care is a medical specialty that helps people facing serious and chronic illness be more comfortable by alleviating pain, treating a host of other symptoms and focusing on their quality of life. It is appropriate at any age and any stage of a serious illness and can be provided along with curative treatment.” In combination, these two definitions of palliative care emphasize the team-based approach that considers each realm of a patient’s health: physical, mental, emotional, and often spiritual, as the patient and his or her caregivers endure health challenges.

When individuals search for the term "palliative care," they often find the phrase "hospice care" alongside it. Hospice care and palliative care are related, but it is crucial to realize that these two are different types of care. Palliative care is meant for any individual dealing with a serious illness or injury and is available at any time throughout the care process. Palliative care focuses on the improvement of symptoms and prompts discussions of what patients desire from their medical care in all realms of health. Palliative care is patient and family needs-based and is separate from disease prognosis. In contrast, hospice care is a type of medical care typically available for individuals who may have less than six months to live. Hospice provides medical care in the patient's home or care facility focused on maintaining comfort in the absence of curative treatments and life-extending therapies.

There is a common misconception among providers and patients that palliative care is only appropriate for individuals who are near the end of life. It is important to understand that all hospice care is palliative care, but not all palliative care is by definition hospice because Palliative medicine may be practiced on individuals that receive curative or life-extending therapies. Palliative Care services can include symptom management, customized plans of care based on patient and family desires, and advance care planning. These services are provided by a specialized team and can be provided in inpatient or outpatient settings.

### **Services Provided**

The defining characteristic of palliative care is its team-based approach. Palliative care is provided by a specially-trained interdisciplinary team typically composed of palliative care physicians, social workers, chaplains, pharmacists, specialists, nurses and nurse practitioners

who work together with a patient's physicians to provide an extra layer of support for the patient, the patient's family, and the patient's physician. Palliative care teams work to treat the underlying physical illness or condition, but also spend time communicating directly with patients and patient families about the care plan and the patient's quality of life. The teams ensure patients understand treatment options and choices. Through a thorough investigation of the patients' personal goals and quality of life standards, the palliative care team is better able to match the individual's goals and treatment plan. This ensures that the patient's personal quality of life standards and treatment goals align with the physician's treatment plan and that the patient understands the often-nuanced medical language within the treatment plan. In addition, the palliative care team coordinates the patient's various doctors and providers and communicates the patient's wishes through all levels of care.

### **Inpatient vs Outpatient PC**

Palliative care covers a wide variety of illnesses and therefore must be available in a variety of settings in order to adequately serve the patient population. To date in the state of Tennessee, Palliative care is predominantly offered in hospital settings. However, a growing body of evidence supports the increased use of palliative care in the outpatient setting. In response to an aging and chronically or seriously ill population, many health systems around the United States are developing new programs to expand access to palliative care beyond the hospital setting to outpatient clinics, offices, and community providers. Even telehealth technologies are increasingly used as Palliative care providers, particularly in rural and underserved areas. The continued development of Palliative care in inpatient and outpatient settings, palliative care services may be better suited to meet patient needs throughout the disease trajectory and continuum of care.

### **Benefits of Palliative Care**

Palliative care services meet the "triple aim" of better health, improved care, and lower cost. A growing body of research demonstrates that palliative care delivered through a broad range of models and care settings improves quality of life, quality of care, and in doing so, reduces hospital costs.

### **Quality of Life**

#### **Quality of Life /Symptom Burden**

The primary benefit of palliative care is increased quality of life and decreased symptom burden for the patient and his or her family. Research suggests that early outpatient and home palliative care may improve patient quality of life<sup>[6]</sup>. Studies also show that, home-based palliative care may increase the chance of dying at home and reduce symptom burden, in particular for patients with cancer<sup>[7, 8]</sup> In addition to cancer patients, individual with life-limiting or serious illness enrolled in a blended outpatient and home palliative care program show improvement in symptoms including anxiety, appetite, dyspnea, well-being, depression and nausea.<sup>[8]</sup> Individuals pursuing curative treatment also fared better overall through participation in palliative care. Patients undergoing chemo radiation who received structured multidisciplinary quality of life (QOL) directed interventions were significantly more likely to complete their treatment as planned compared to patients who did not receive the QOL intervention<sup>[9]</sup> Irrespective of age, gender, and type of tumor, patients taken into care by the palliative home-care team were more

likely to die at home, less likely to be hospitalized, and spent fewer days in hospital in the last 2 months of their life<sup>[10]</sup>

## **Quality of Care**

### **Family / Caregiver**

Apart from being the best choice for patient well-being, a better quality of life for the patient and patient families also means that encounters with the health care system are less stressful and traumatic.<sup>[11]</sup> For many individuals palliative care is a crucial piece in their care path. Earlier palliative care consultation has been associated with higher satisfaction with care overall<sup>[12]</sup> and consultations with Palliative specialists have been associated with reductions in family distress<sup>[13]</sup>. Overall, the palliative care model helps patients to communicate with the health care system without added stress and increases patient satisfaction while decreasing familial or caregiver distress.

### **Admissions/Readmissions**

Palliative care also offers benefits not only to patients, but also the overall healthcare system by reducing admissions and 30-day rehospitalizations. By reducing 30-day readmissions, palliative care has an important role to play in post-acute care and overall care quality. This benefit is seen in both the inpatient and outpatient settings. Hospitalized individuals who have a palliative care consult have a significantly lower 30-day readmission rate than patients who had no palliative care consultation. This was especially true when palliative care consultations involved goals of care discussions, which were associated with a 74% lower readmission rate<sup>[14, 15]</sup>. In home-based palliative care, patients' hospital admissions were reduced by 34% in the final month<sup>[16]</sup>.

## **Cost Reduction**

### **Cost**

Nationally, spending on health care accounts for 17.5 percent of the United States GDP; however, a majority of this spending is concentrated in a relatively small percentage of the population. Total spending on Medicare beneficiaries in their last year of life accounts for about 13.5% of total Medicare spending.<sup>[17]</sup> Seriously ill patients compose the top 5%-10% of individuals but account for approximately 50% of Medicare spending in the US. Separated by age group, annual expenditures among the top 5 percent of spenders averaged \$62,472 for adults ages 45-64 and \$68,819 for adults ages 65 and older. This is significantly higher than healthier individuals in the same age groups<sup>[18]</sup>. Palliative care provides a possible tool that could be used to reduce overall spending on end-of-life care without decrease in patients or caregiver satisfaction. Research suggests that non-cancer patients with at least six months of palliative care exposure, similar to the top 5-10% of Medicare spenders, showed an average decrease in total hospital charges of nearly \$275,000<sup>[19]</sup>. This cost reduction is particularly effective when the palliative care consultation happens early in the hospital admission. When the consultation happens within 2 days, a 24% reduction (approximately \$2,280) is seen. When the consultation occurs within six days, a 14% cost savings is seen.<sup>[20]</sup> For individuals with home-based palliative care, the cost per patient during the final three months of life was \$12,000 lower than individuals with usual care (\$20,420 vs. \$32,420)<sup>[16]</sup>. The inclusion of palliative care in the medical model is crucial to future conversations surrounding cost-reduction.

## Findings

### Research and Data

A significant finding of the taskforce was the gaps in user friendly data on the existence and location of palliative care providers throughout the state. These gaps exist across the palliative care workforce, including multiple professions and degrees. Although each certifying board maintains its own database of physicians, there is no central means by which to locate palliative care physicians. Although there is a national initiative by Center to Advance Palliative Care (CAPC) to map community-based palliative care programs, there is no reliable or centralized method to assess the number of palliative care physicians, certified midlevel providers, nurses, social workers, and others on the palliative care team.

### Maps of where PC is offered in our State

In regards to Tennessee, palliative care staffing in hospitals is similar to that of other southeastern states, however, the state remains far behind the national average.<sup>[21]</sup> One significant finding of the taskforce was the geographic variation in the availability of palliative care throughout Tennessee. According to the Task Force findings, there are hospitals throughout the state that offer palliative care, but not all have beds or units specifically designated for this service. Geographic gaps among board certified palliative physicians proved stark in comparison. A significant gap exists in Northwest Tennessee, parts of Southern middle Tennessee, and the Upper Cumberland regions. Nearly all of the palliative care physicians are located in metro and surrounding areas. Similar to hospitals, there appeared to be a complete lack of board certified palliative care physicians in Northwest Tennessee and the Upper Cumberland region. These workforce shortages contribute to limited access to palliative care among older adults, especially those living in rural areas of the state.

### Graduate Medical Education (GME)

Graduate medical education (GME) is the supervised hands-on training after medical school that all physicians must complete in order to be licensed and practice independently. In Tennessee there are GME programs specifically for palliative care at two medical schools, University of Tennessee Health Science Center College of Medicine and Vanderbilt University Medical School. The University of Tennessee program began in 2014 and has 4 designated GME slots for palliative care each year. Vanderbilt University program began in 2010 and has 3 slots each year. Both schools have consistently filled each of these slots with successful candidates over the past several years. The majority of physicians completing each of these programs remain in Tennessee after completion of the program (14 of 26). This high in-state retention suggests the potential for a way by which to grow Tennessee's palliative care provider network.

### Mid-level providers, nurses, etc.

In addition to formalized education programs for physicians, there are also specific programs geared towards mid-level providers and allied health. Master's level nursing programs may offer a specialty or certificate in palliative care medicine. In Tennessee there are 14 masters level nursing education programs (Appendix C). However, according to the Hospice and Palliative Nursing Association (HPNA), none have programs specific to palliative care.<sup>[22]</sup> However, Vanderbilt University School of Nursing does offer elective courses in palliative care.

For social workers in hospice and palliative care who meet credentialing requirements, the National Association of Social Workers provides certification for Certified Hospice and Palliative Social Worker (CHP-SW) for bachelor's level social workers and Advanced Certified Hospice and Palliative Social Worker (ACHP-SW) for master's level social workers. There is no currently available data on the number of social workers with this certification in Tennessee.

## Barriers

The taskforce identified barriers to access and utilization of palliative care from several perspectives including: physician/medical provider, patient/family, and organizational/structural.

### **Physician/medical provider**

Significant barriers at the provider level include workforce shortages, insufficient education, and lack of communication and coordination between the provider networks. Hospice and palliative care is now an established medical specialty, and palliative care has a strong presence in clinical education, professional organizations, and research communities. While education of health professionals who provide care to patients at the end of life has substantially improved in recent decades, professional development is needed for all medical providers to support palliative care. Communication and coordination are key components to offering high-quality, well-coordinated palliative care but can prove difficult across multiple settings. Common misconceptions among medical professionals, such as the idea that palliative care is only appropriate for patients near death can present barriers to patient needs.<sup>[23]</sup>

There is a strong need to build support for public and institutional policies that ensure high-quality, sustainable care exists throughout the state; that assertion is based on the general confusion of palliative care with hospice or the lack of knowledge about palliative care as an option throughout the care continuum. The question of when to refer a patient to palliative care is crucial to investigate, but may differ on a patient by patient basis. Overall, discussion among palliative care providers would help address questions pertaining to referral point, the common misconception that palliative care is appropriate solely for patients near death<sup>[15]</sup>, and coordination with electronic medical records. These conversations would benefit providers at all levels and the inclusion of nurse practitioners throughout the state is crucial for maximum patient reach.

### **Patient / Family**

At the community and family levels a need exists to raise awareness and elevate expectations about care options, the needs of caregivers, and the hallmarks of high-quality care in a confusing medical system. At the individual level, there is a need to motivate and facilitate advance care planning and meaningful conversations with family members and caregivers about an individual's quality of life and care standards.

In-depth conversation about available treatment options, patients' personal values, needs and goals for quality of life can address some of the patient and family barriers identified. Comprehensive palliative care information written in plain language could support patients, families, and caregivers while raising awareness and decreasing stigma. Increased understanding, identifying whether it is right for the individual, and taking steps to access palliative care will help address barriers.

For the patient, palliative care focuses on relief from physical suffering by addressing the patient's physical, mental, social, and spiritual well-being through a team approach using specially trained professionals. A palliative care patient may be living with or getting treated for a chronic disease which may or may not be terminal. Accurate information about palliative care

would work to increase public awareness and decrease the stigma that often accompanies this type of care. According to providers on the Task Force, patients are often concerned when palliative care is mentioned in the care plan because the individuals equate palliative care with hospice. Medical providers could use the plain language tool in addition to the establishment of a patient-provider connection that allows the patient to become his or her own advocate.<sup>[24]</sup>

### **Organizational/structural**

Due to these barriers at all levels, disparities between the usage and access of palliative care continue to persist. Broadly defined, disparities in health and healthcare are differences in the presence of disease, health outcomes, quality of care, and access to care that exist across populations or groups of people. These disparities can occur across racial/ethnic groups, geographic areas, and care settings. For example, studies consistently document lower rates of hospice use for minority older adults than for whites across diagnoses, geographic areas, and settings of care, including nursing homes.<sup>[25]</sup> In addition hospice use is lower in rural areas.<sup>[26]</sup> Unfortunately, research is minimal on disparities in the use of non-hospice based palliative care. However, through maps and other research, it is clear that access is not uniform across the state. There are fewer providers and fewer palliative care units in Tennessee's rural areas.

Throughout the Task Force meetings, challenges related to medical billing and payment models were discussed. One complexity mentioned was the existing ICD-10 code for palliative care. Currently, this code cannot be listed as the primary diagnosis within the current billing system physicians use to be reimbursed for services. Another challenge brought up by several task members was the payment structure of the Fee for Service system. Task Force members suggested that through a value based system or alternative payment models, palliative care may become more accessible to additional providers and patients.

## Recommendations

**Recommendation 1.** Establish a State Advisory Council on Palliative Care and Quality of Life within the Tennessee Commission on Aging and Disability to consult with and advise the Executive Director, Tennessee General Assembly, and other state agencies on matters related to the establishment, maintenance, and operation of palliative care initiatives in this state.

**Strategy a.** In recognition of confusion surrounding the definition of palliative care and fundamental differences between palliative care and hospice care, the Council will adopt a clear definition of palliative care, in order to provide clarity and begin to educate healthcare practitioners and the public.

**Strategy b.** Review existing barriers to palliative care access.

**Strategy c.** Develop best practice standards for reduction of disparities in access to palliative care including disparities between rural and urban settings, various cultural racial and ethnic groups, and different socioeconomic groups.

**Strategy d.** Provide a yearly report on the State of Palliative Care in Tennessee.

**Recommendation 2.** Ensure that comprehensive and accurate information and education on palliative care is available to the public, health care providers, and health care facilities through the maintenance of a statewide Palliative Care Information and Education Program in the American Cancer Society Cancer Action Network.

**Strategy a.** Clearly define what palliative care is and how it can help those facing serious illness.

**Strategy b.** In partnership with local associations and national organizations, create an online directory of palliative care resources, including a registry of palliative care providers to service health care facilities and providers.

**Strategy c.** Develop a resource guide to provide additional education about this resource for community partners.

**Recommendation 3.** Explore potential funding opportunities for pilot projects to advance quality of life for Tennesseans including, but not exclusive to, federal grants, state funded graduate medical education, or quality improvement grants.

**Strategy a.** Apply for potential grant funding and research other funding sources.

**Strategy b.** Track and report outcomes that demonstrate improved quality care.

**Strategy c.** Partner with health care entities and initiatives throughout the state of Tennessee to draft and develop measurable and scalable evidence-based palliative care initiatives.

**Recommendation 4.**

Study and understand current payment models and their impact on health care costs surrounding the use of palliative care in the state of Tennessee.

**Strategy a.** Technical assistance provided to plans should include instruction in different methods for assessing palliative care programs' impact on health care utilization and total health care cost analyses.

**Strategy b.** Develop and study alternate payment models in order to allow palliative care to be more accessible to additional providers and patients

**Recommendation 5.**

Communicate directly with the different members of the palliative care system (clinicians, social workers, patient advocates, etc.) and the associations that represent these members to glean an accurate understanding of the strengths, weaknesses, and needs of the palliative care workforce in Tennessee.

**Strategy a.** Understand what specialty palliative services are currently available, opportunities for leveraging existing non-palliative programs to meet needs, and how to deliver education and other supports to non-specialist providers.

**Strategy b.** Disseminate examples of community-based palliative care models, representing a wide variety of team structures and care settings.

**Strategy c.** Consider how to most effectively triage the palliative care needs of their members, emphasizing generalist-level palliative care services for the majority of members, and reserving specialty-level palliative care services for members with specific needs.

## **Appendices**

## Appendix A – State by State Palliative Care Legislation

### Advisory Focused:

1. Arkansas
  - Palliative Care and Quality of Life Interdisciplinary Task Force, established 2017
  - Purpose: provide “recommendations for the establishment, maintenance, operation and outcome evaluation of palliative care initiatives in the state and recommendations for any statutory changes.”
  - Submission of a report to the Governor and Legislature before January 2019, follow-up report before December 31, 2020 detailing implementation of recommendations
2. Connecticut
  - Palliative Care Advisory Council established 2014
  - Purpose: “Analyze current state of palliative care in CT and advise Department of Public Health on matters related to improving palliative care and quality of life for people with serious or chronic illnesses.”
  - Submission of yearly reports from 2014-2016: definitions of palliative care and establish state barriers to care.
3. Georgia
  - Palliative Care and Quality of Life Advisory Council established 2016
  - Purpose: “consult with and advise Department of Community Health on matters related to the establishment, maintenance, operation and outcomes evaluation of palliative care initiatives in the state.”
  - Each member serves for a 3-year period, December 2016 only minutes available for public viewing state that the Council would submit a report by June 30<sup>th</sup>, 2016
4. Maryland
  - Hospital Palliative Care Pilot Project, established 2013
  - Purpose: Maryland Health Care Commission to develop a hospital palliative care pilot program to report certain findings and recommendations to the General Assembly
  - Recommendations used to develop minimum standards for palliative care programs with goal of expanding access to services by July 2016
  - Final report issued December 1<sup>st</sup>, 2015
5. Massachusetts
  - Palliative Care and Quality of Life Interdisciplinary Advisory Council, established 2015
  - Purpose: “Consult with and advise the Department Health of on matters related to establishment, maintenance, operation and evaluation of palliative care initiatives in the commonwealth.”
  - Department of Health then reports findings and resources on website
  - Last meeting January 2016
6. Rhode Island
  - Palliative Care and Quality of Life Interdisciplinary Council, established 2013
  - Purpose: Consult with and advise department of health on matters related to “establishment, maintenance, operation and outcomes evaluation” of palliative care initiatives in the state
7. Texas
  - Palliative Care Interdisciplinary Advisory Council, established 2015
  - Purpose: Assess availability of patient-centered and family-focused palliative care in the state
  - Advise Texas Health and Human Services Commission on “matters related to establishment, maintenance, operation and outcome evaluation of statewide palliative care consumer and professional information and education program.”
    - Biennial report assessing:
    - Availability of palliative care in Texas

- Barriers to access
- Policies, practices and protocols concerning patients' rights

**Education Focused:**

8. Alabama
  - State Advisory Council created in 2015
  - Purpose: Establish a palliative care consumer and professional information and education program
  - Meets quarterly
  - Discuss a range of topics (i.e. Decision Makers to CMS payment reform) with the purpose of education for all fields involved in the palliative care process.
9. Alaska
  - Alaska Health Care Commission End of Life Care, established 2010
  - Purpose: Public education of End of Life Care issues
  - Original Commission delivered a report to AK Governor on January 15, 2010
  - Website last updated in 2012, last meeting in February of 2015
10. Missouri
  - Palliative Care and Quality of Life Interdisciplinary Council, established 2016
  - Purpose: "Palliative care consumer and professional information and education program to improve quality and delivery of patient centered and family-focused care."
  - Members serve 3-year terms
  - No details on meetings online currently
11. New Hampshire
  - Palliative Care Center for Health Care Consumers and Providers, established 2014
  - Purpose: "To monitor the state of palliative care in New Hampshire and to educate health care consumers and providers."
  - Bill text revised in 2016, no further action found in online resources

**Dual Purpose:**

12. Indiana
  - Palliative Care and Quality of Life Advisory Council, established 2017
  - Purpose:
    - "Educate and advocate for quality palliative care by requesting that the state department establish forums, programs, or initiatives"
    - "Collect, analyze, advise on and develop state initiatives"
    - "Make policy recommendations to improve palliative care"
    - "Prepare report by January 1 of each year concerning findings"
  - First meeting held on September 21, 2017, no information online
13. Maine
  - Palliative Care and Quality of Life Advisory Council, established 2015
  - Purpose:
    - "Advise Maine CDC on matters related to palliative care initiatives in the state"
    - "Analyze palliative care being provided in the state"
    - "Make recommendations to improve palliative care"
    - "Submit a report by January 1<sup>st</sup> each year with findings and recommendations"
  - Publicly available report: 2016 report on the number of health centers and palliative programs throughout the state
14. Montana
  - Palliative Care and Quality of Life Advisory Council, established 2017

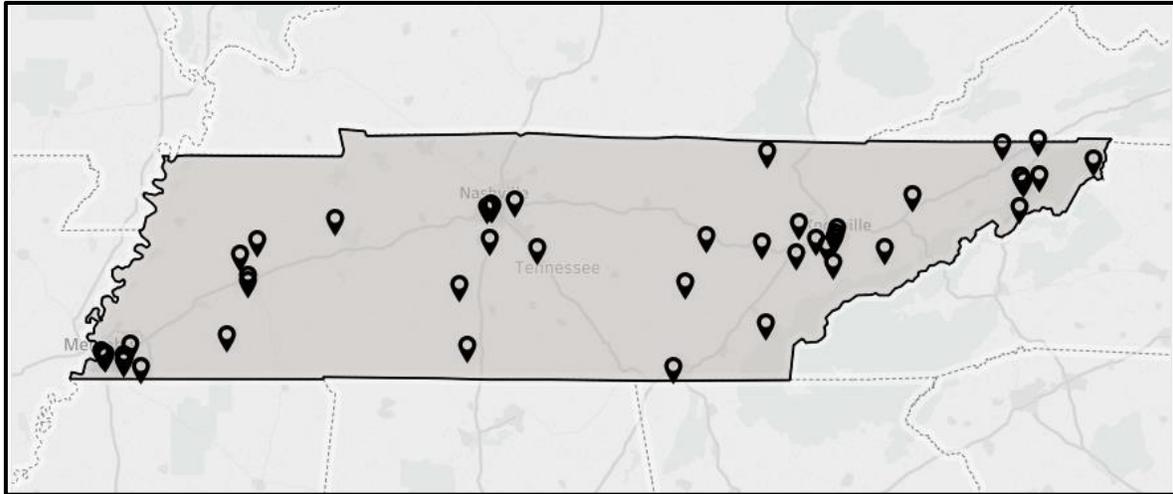
- Purpose: “Educate the public and health care providers about palliative care” through online repository of resources about services, including continuing educational opportunities for providers.
  - Council will make recommendations to the state, specifics not yet established
15. Nebraska
- Palliative Care Consumer and Professional Information and education Program, established 2017
  - Creation of Palliative Care and Quality of Life Advisory Council
  - Purpose: Make following information publicly available online by June 30, 2018
    - Continuing education opportunities
    - Delivery of palliative care in home and levels of inpatient centers
    - Best practices
    - Educational materials
    - Referral information
    - Palliative care delivery systems
16. Oklahoma
- Home Care, Hospice, and Palliative Care Advisory Council, established 2014
  - Purpose:
    - Identify methods to improve quality an delivery of home care, hospice and palliative care
    - Review best practices
    - Develop information on home care, hospice, and palliative care for general public
  - Council meets at least twice a year, able to recommend rules to State Board of Health after public comment
17. Oregon
- Palliative Care and Quality of Life Interdisciplinary Advisory Council, established 2015
  - Purpose: Improve lives of children, youth, adults and the elderly who would benefit from palliative care and facilitate access through better care coordination.
  - Council meets at least twice a year
  - Consults and advises Oregon Health Authority on palliative care issues
18. Vermont
- Palliative Care and Pain Management Task Force, established 2009
  - Purpose: Coordinate palliative care and pain management initiatives in Vermont though information sharing and network development
    - Increase access to services
    - Propose solutions to address service gaps
    - Educate consumers about rights under palliative care legislation
  - Last annual report issued in 2014
19. Wyoming
- Palliative Care Advisory Council, established 2017
  - Purpose: Educate public and medical providers on issues surrounding palliative care
  - Partner with department of health to evaluate quality of state-wide care and recommend legislative action

**Unknown status:**

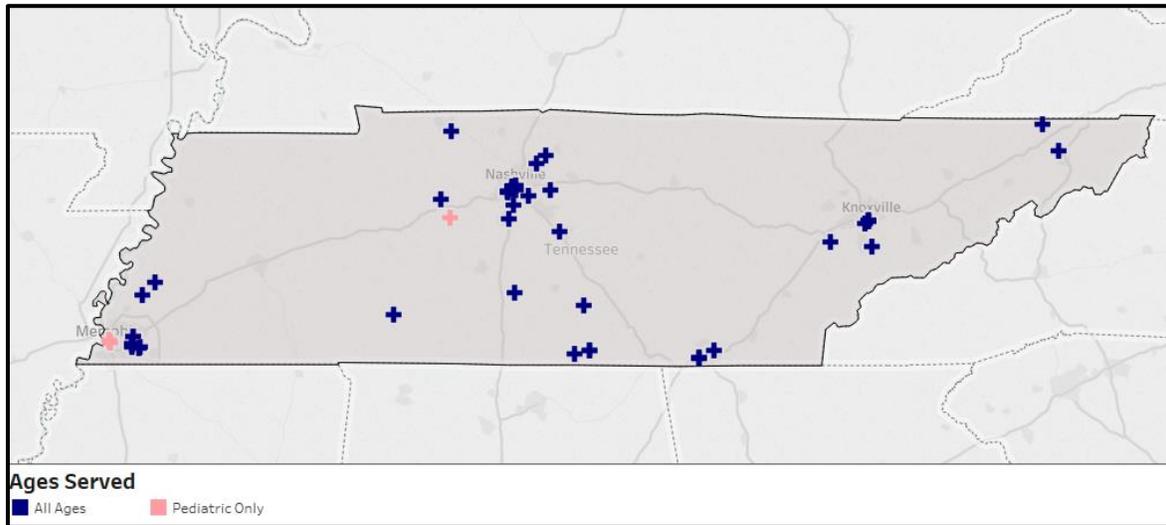
20. Illinois
- Hospice and Palliative Care advisory Board, established 2008
  - Information not available online

## Appendix B – Maps of Palliative Care in Tennessee

### Hospitals Providing Palliative Care



### Palliative Care Physicians



## Appendix C – Masters Level Nursing Education Programs

Austin Peay State University

Belmont University

Carson-Newman College

East Tennessee State University

King University

Middle Tennessee State University

Tennessee Technological University

Tennessee State University

The University of Tennessee Health Science Center

Union University

University of Memphis

University of Tennessee at Chattanooga

University of Tennessee, Knoxville

Vanderbilt University

## Appendix D – Glossary of Key Terms <sup>[27]</sup>

**Advance directive** - A general term that describes two kinds of legal documents, living wills and medical powers of attorney. These documents allow a person to give instructions about future medical care should he or she be unable to participate in medical decisions due to serious illness or incapacity. Each state regulates the use of advance directives differently.

**Hospice** - Considered to be the model for quality, compassionate care for people facing a life-limiting illness or injury, hospice and palliative care involve a team-oriented approach to expert medical care, pain management, and emotional and spiritual support expressly tailored to the person's needs and wishes. Support is provided to the persons loved ones as well.

**Palliative care** - A comprehensive approach to treating serious illness that focuses on the physical, psychological and spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering and controlling pain and symptoms.

## Bibliography

- [1] The Dartmouth Atlas of Health Care, "Physician Visits per Decedent, by Interval Before Death and Specialty," Lebanon, NH.
- [2] Stanford School of Medicine. Palliative Care, "Where do Americans die?," 2018. [Online]. Available: <https://palliative.stanford.edu/home-hospice-home-care-of-the-dying-patient/where-do-americans-die/>.
- [3] J. Cubanski, T. Neuman, S. Griffin and A. Damico, "Medicare Spending at the End of Life: A Snapshot of Beneficiaries Who Died in 2014 and the Cost of Their Care," Kaiser Family Foundation, 2016.
- [4] J. S. Temel, J. A. Greer, A. Muzikansky, E. R. Gallagher, S. Adamane, V. A. Jackson, C. M. Dahlin, C. D. Blinderman, J. Jacobsen, W. F. Pirl, J. A. Billings and T. J. Lynch, "Early Palliative Care for Patients with," *New England Journal of Medicine*, pp. 733-42, August 2010.
- [5] L. Sweeney, A. Halpert and J. Waranoff, "Patient-centered Management of Complex Patients Can Reduce Costs Without Shortening Life," *The American Journal of Managed Care*, February 2007.
- [6] M. Davis, J. Temel, T. Balboni and P. Glare, "A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses.," *Annals of Palliative Medicine*, vol. 4, no. 3, pp. 99-121, 2015.
- [7] B. Gomes, N. Calanzani, V. Curiale, P. McCrone and I. Higginson, "Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers.," *The Cochrane Database of Systematic Reviews*, vol. 6, 2013.
- [8] C. Kerr, J. Tangeman and C. Rudra, "Clinical impact of a home-based palliative care program: a hospice-private payer partnership.," *Journal of Pain Symptom Management*, vol. 48, no. 5, pp. 883-892, 2014.
- [9] A. Cheville, S. Alberts, R. Rummans, J. Basford, M. Lapid, J. Sloan, D. Satele and M. Clark, "Improving Adherence to Cancer Treatment by Addressing Quality of Life in Patients With Advanced Gastrointestinal Cancers," *Journal of Pain and Symptom Management*, vol. 50, no. 3, pp. 321-7, 2015.
- [10] M. Riolfi, A. Buja, C. Zanardo, C. Marangon, P. Manno and V. Baldo, "Effectiveness of palliative home-care services in reducing hospital admissions and determinants of hospitalization for terminally ill patients followed up by a palliative home-care team: a retrospective cohort study," *Palliative Medicine*, vol. 28, no. 5, pp. 403-11, 2014.
- [11] D. Kavalieratos, J. Corbelli, D. Zhang, J. Dionne-Odom, N. Ernecoff, J. Hanmer, Z. Hoydich, D. Ikejiani, M. Klein-Fedyshin, C. Zimmermann, S. Morton, R. Arnold, L. Heller and Y. Schenker, "Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis," *JAMA*, vol. 316, no. 20, pp. 2104-2114, 2016.
- [12] D. Casarett, S. Shreve, C. Luhrs, K. Lorenz, D. Smith, M. DeSousa and D. Richardson, "Measuring families' perceptions of care across a health care system: preliminary experience with the Family Assessment of Treatment at End of Life Short form (FATE-S)," *Journal of Pain and Symptom Management*, vol. 40, no. 6, pp. 801-9, 2010.
- [13] G. Smith, R. Bernacki and S. Block, "The role of palliative care in population management and accountable care organizations," *Journal of Palliative Medicine*, vol. 18, no. 6, pp. 486-94, 2015.
- [14] S. Enguidanos, E. Vesper and K. Lorenz, "30-Day readmissions among seriously ill older adults," *Journal of Palliative Medicine*, vol. 15, no. 12, pp. 1356-61, 2012.

- [15] N. O'Connor, M. Moyer, M. Behta and D. Casarett, "The impact of inpatient palliative care consultations on 30-day hospital readmissions.," *Journal of Palliative Care Medicine*, vol. 18, no. 11, pp. 956-961, 2015.
- [16] D. Lustbader, M. Mudra, C. Romano, E. Lukoski, A. Chang, J. Mittelberger, T. Scherr and D. Cooper, "The Impact of a Home-Based Palliative Care Program in an Accountable Care Organization," *Journal of Palliative Medicine*, vol. 20, no. 1, pp. 23-28, 2016.
- [17] S. Griffin, J. Cubanski and T. Neuman, "Medicare and End-of-Life Care," *JAMA*, vol. 316, no. 17, p. 1754, 2016.
- [18] E. M. Mitchell, "Concentration of Health Expenditures in the U.S. Civilian Noninstitutionalized," *Agency for Healthcare Research and Quality, Statistical Brief #497*, November 2016.
- [19] A. Postier, J. Chrastek, S. NUgent, K. Osenga and S. Friedrichsdorf, "Exposure to home-based pediatric palliative and hospice care and its impact on hospital and emergency care charges at a single institution," *Journal of Palliative Medicine*, vol. 17, no. 2, pp. 183-188, 2014.
- [20] M. L. Anderson, A. W. Mann, A. Nitsch, M. K. Schlepp, M. Hoegh and S. Raghavan, "Early Palliative Care Can Save Money," *The Hospitalist*, vol. 2015, no. 12, 2015.
- [21] National Palliative Care Registry, "Tennessee, Palliative Care in Your State's Hospital," 2015.
- [22] Hospice and Palliative Nurses Association, "Graduate Program Listing," 2013. [Online]. Available: <http://advancingexpertcare.org/graduate-program-listing/>.
- [23] J. E. Nelson, E. Azoulay, J. R. Curtis, A. C. Mosenthal, C. Mulkerin, K. Puntillo and M. D. Siegel, "Palliative Care in the ICU," *Journal of Palliative Medicine*, vol. 15, no. 2, 2012.
- [24] Department of Health and Human Services, Centers for Medicare & Medicaid Services, "Palliative Care vs. Hospice Care, Similar but Different," June 2015. [Online]. Available: <https://www.cms.gov/Medicare-Medicaid-Coordination/Fraud-Prevention/Medicaid-Integrity-Education/Downloads/infograph-PalliativeCare-%5bJune-2015%5d.pdf>.
- [25] K. S. Johnson, "Racial and Ethnic Disparities in Palliative Care," *Journal of Palliative Medicine*, vol. 16, no. 11, pp. 1329-1334, 2013.
- [26] Medicare Payment Advisory Commission, "Report to the Congress: Medicare Payment Policy Chapter 12," 2017.
- [27] National Hospice and Palliative Care Organization, "Glossary," [Online]. Available: <http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3408>. [Accessed December 2017].

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