



State Palliative Care and Quality of Life Advisory Council

2019 Update Report

4/1/2019

Contents

What is Palliative Care?..... 1

Palliative Care Advisory Council Members 2

Introduction 3

Adopted Definition of Palliative Care 4

Goals of Palliative Care Advisory Council..... 5

Summary of the Advisory Council Meetings..... 6

Recommendations 9

Appendices..... 10

Appendix 1 11

Appendix 2 14

Appendix 3 16

Appendix 4 20

What is Palliative Care?

Palliative care is specialized care for people facing *serious illness*¹, focusing on providing relief of suffering (physical, psychosocial, and spiritual), to maximize quality of life for both the patient and family.

1-Within palliative care, serious illness is defined as a health condition that carries a high risk of mortality and a) negatively impacts a person's daily function, b) negatively impacts a person's quality of life, and/or c) excessively strains the person's caregiver.

When is Palliative Care Appropriate?

Patients who are coping with a serious illness can benefit from palliative care at any time during their treatment. These patients may still be receiving treatment aimed at a cure. Palliative care is provided by a team of trained healthcare professionals who offer services such as:

- Providing relief from pain and other physical symptoms
- Improving quality of life
- Providing support to the seriously ill and the family and friends who love and care for them
- Assisting the patient, family and staff with difficult medical decision-making

Palliative care works as a complimentary supplement to a patient's usual medical treatment and is available to patients at any stage of illness to help manage symptoms of their treatment.

Who Provides Palliative Care?

Doctors and nurse practitioners: evaluate and treat symptoms, assist with complicated medical conversations and situations that occur at the end of life, and will help establish goals of care that are consistent with beliefs, values, and wishes.

Case managers: provide resources and placement options and work with members of the primary team to coordinate home needs, nursing facility placements, or hospice support when appropriate.

Social workers: provide emotional and social support and help understand health care planning for the future, such as creating an advance care plan.

Pastoral care: maintaining the important role that faith and spirit play in the lives of patients.

Child life specialists: meet with children and their families to help discuss and understand difficult situations that a patient may face.

Pharmacy staff: ensure that prescriptions are accurate and assist in the acquisition of unusual or difficult-to-obtain medications necessary to treat symptoms.

Palliative Care Advisory Council Members

Justin Baker, MD, FAAP, FAAHPM

Chief, Division of Quality of Life and Palliative Care

St. Jude Children's Research Hospital

Linda Estes, RN, BS, NHA

Director of Quality and Regulatory Affairs

Tennessee Health Care Association

Karen Hyden, APN-BC, MSN/Ed, ACHPN

Board Certified Palliative Care and Hospice

Nurse Practitioner

Compassus

Clay Jackson, MD, DipTh

Clinical Assistant Professor of Family Medicine and Psychiatry

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Mohana Karlekar, MD

Director, Vanderbilt University Palliative Care

Assistant Medical Program Director, Medical Palliative Care Fellowship

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Maria Vilmerding Moore

Executive Hospice Care Consultant

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Kindred at Home

Anna Gene O'Neal

President & CEO

Alive Hospice

Jill Patterson, NP

University Palliative Care

Greg Phelps, MD, MPH. MAHCM

Chief Medical Officer

Hospice of Chattanooga

Sally Pitt

Director, Office of Patient Care Advocacy

Tennessee Department of Health

Tammy Stokes, BSN, CHPN, RN

Director of Palliative Care

Maury Regional Medical Center

Jim Shulman, JD

Executive Director

Tennessee Commission on Aging and Disability

Introduction

In 2018, the Tennessee State Palliative Care and Quality of Life Council was enacted as Public Chapter 955 (see Appendix 1).

This act establishes an 11-member Palliative Care Advisory Council within the Tennessee Commission on Aging and Disability (TCAD). The purpose of the Council is to (1) continually assess the current status of palliative care in the state and to review the barriers that exist that prevent such care from being obtained and utilized by the people who could benefit from such care and (2) provide recommendations to the governor and to the general assembly on issues related to its work.

The act, which became effective on April 24, 2018, requires the Council to begin annually reporting its findings and recommendations to the Governor and General Assembly, beginning in January, 2020. This report serves as an update.

The Council members include health professionals having palliative care work experience or expertise in palliative care delivery models in a variety of inpatient, outpatient, and community settings such as acute care, long-term care, and hospice, and with a variety of populations, including pediatric, youth, and adult. The Council is required to include at least one (1) board-certified hospice and palliative medicine physician, at least one (1) be a licensed certified registered nurse practitioner with expertise in palliative care, and one (1) member shall be from the Tennessee Department of Health.

The members serve three-year terms without compensation and must elect a chair and vice chair. The Council must meet regularly and no less than twice yearly.

To date, the Council has met four times. The early meetings focused on the first charge in the law, to “assess the current status of palliative care in the state and to review the barriers that exist that prevent such care from being obtained and utilized by the people who could benefit from such care”. Recognizing that confusion exists regarding what palliative care is, the Council first developed a working definition of palliative care, in order to be speaking a common language and as a beginning step in educating healthcare practitioners and the public.

Adopted Definition of Palliative Care

Palliative care is specialized care for people facing *serious illness*¹, focusing on providing relief of suffering (physical, psychosocial, and spiritual), to maximize quality of life for both the patient and family.

1-Within palliative care, serious illness is defined as a health condition that carries a high risk of mortality and a) negatively impacts a person's daily function, b) negatively impacts a person's quality of life, and/or c) excessively strains the person's caregiver.

This definition was adopted by the State Palliative Care and Quality of Life Advisory Council on January 30, 2019.

Goals of Palliative Care Advisory Council

Goal 1 - Continually assess the current status of palliative care in the state and to review the barriers that exist that prevent such care from being obtained and utilized by the people who could benefit from such care

Goal 2 - Provide recommendations to the governor and to the general assembly on issues related to its work

Summary of the Advisory Council Meetings

August 22, 2018

The Palliative Care Advisory Council met a total of four times between August, 2018 and January, 2019. The initial meeting took place via conference call on August 22, 2018 with The primary purpose of appointing a chairperson and reviewing the purpose and legislative intent of the Council. Mr. Shulman made the motion that Dr. Mohana Karlekar serve as Chair of the Council. Council members agreed unanimously. Dr. Karlekar reviewed the purpose of the Council, led a discussion of expectations, and requested input from Council members on meeting content and structure. Council members requested a legislative history, legislative review of other states, and a discussion on practical steps to address initial priorities set by the 2018 State Palliative Care and Quality of Life Taskforce. Council members decided to hold the next meeting in conjunction with the Palliative Care Conference sponsored by St. Jude Children's Research Hospital and the Tennessee Hospital Association.

September 26, 2018

The second meeting of the Council took place on September 26, 2018 in Memphis, TN and was held in conjunction with the Palliative Care Conference sponsored by St. Jude Children's Research Hospital and the Tennessee Hospital Association. The focus of this meeting was the initial priorities as set forth by 2018 State Palliative Care and Quality of Life Taskforce. The first priority identified was the development of a unified definition of Palliative Care, in order to more clearly define the Council's work. The definitions developed by other national groups were presented and discussed. After discussion, the following definition was adopted unanimously by voice vote.

Palliative care is specialized care for people facing *serious illness*¹, focusing on providing relief of suffering (physical, psychosocial, and spiritual), to maximize quality of life for both the patient and family.

1-Within palliative care, serious illness is defined as a health condition that carries a high risk of mortality and a) negatively impacts a person's daily function, b) negatively impacts a person's quality of life, and/or c) excessively strains the person's caregiver.

Dr. Clay Jackson, who serves on TN Board of Health Commission on Chronic Pain, stated he would like to present this definition to the Commission and ask if they will incorporate it into the appendices of the "Tennessee Chronic pain Guidelines."

The Council set agenda for third meeting to include a review barriers for palliative care, , a brief history of the State Palliative Care and Quality of Life Taskforce, and a legislative review from other states

TCAD staff collected and compiled a list of barriers, history of Taskforce (Appendix 2), and legislative review (Appendix 3) and distributed to all Council members prior to third meeting.

November 7, 2018

The third meeting of the Council took place on November 7, 2018 with a focus on barriers to palliative care access. Prior to this meeting, TCAD staff collected and compiled a list barriers identified by Council members (Appendix 4). After review, the barriers were grouped into three categories: 1) Organizational, 2) Systematic, 3) Societal. The Council discussed the barriers in each category and decided which to focus on based on priority and likelihood of a solution.

Within the organizational barriers, the Council decided to focus on lack of awareness of palliative care by both patient/family and providers. To address this barrier, Council members discussed marketing and outreach initiatives including a statewide palliative care conference.

Within the systematic barriers, the Council discussed lack of funding, availability across settings, trained providers/programs, and standardization. To address these barriers, Council members discussed research opportunities including national and state funding models and training opportunities. Additionally, the Council discussed production of a TN Palliative Care Provider Directory and publication of information, both written and online. Additional research is needed to determine what data is currently being collected and how to standardize this process.

Societal barriers were addressed in the previous two categories.

The Council discussed strategies to address these barriers, including a statewide education initiative. The Chair suggested a sub-group form to discuss an education and outreach plan, including, the potential for a statewide conference. Six Council members volunteered to serve on the Statewide Education and Outreach Sub-Committee.

January 30, 2019

The fourth meeting of the Council took place on January 30, 2019 with a focus on recommendations. The Council heard from national speakers representing Center to Advance Palliative Care (CAPC) who presented best practices from other State Advisory Councils. Best practices included early adoption of a definition of palliative care, strategic messaging, and utilization of national organizations (ex. National Academy for State Health Policy in which Tennessee is represented). Next, presenters gave an overview of current palliative care mapping projects happening in other states and nationally. Mapping can make it easier for patients, families, caregivers, and practitioners to find programs and identify gaps in services in their area. For example, through mapping Florida identified the capacity of palliative care services in their state. Nationally, CAPC is mapping hospital based palliative care and is encouraging states to help drive this mapping process. Presenters gave further information on how other states partner with state

and national entities to address Council goals. This information will be utilized when forming this Council's future meeting agendas.

Next, the Advisory Council discussed recommendations related to access, education, partnerships, and communication. Different strategies to meet recommendations were discussed. Recommendations and strategies will be submitted through an update report to the Governor and General Assembly.

Then, the Advisory Council discussed legislative recommendations for 2019. After reviewing the adopted definition of palliative care, a motion was made to recommend palliative care be added to Tenn. Code Ann. § 63-1-164. This motion passed unanimously.

Finally, an update on the upcoming State Palliative Care Conference was given. The Council was asked by the Tennessee Department of Health to submit a budget for conference funding. If funding is received, the conference will be held Friday, September 27, 2019 in Brentwood, TN. Diane Meier, Director of the Center to Advance Palliative, has agreed to be the keynote speaker. The Statewide Education and Outreach Sub-Committee will continue to meet to discuss agenda topics.

Recommendations

Recommendation 1. In recognition of confusion surrounding the definition of palliative care and fundamental differences between palliative care and hospice care, adopt the Council-approved definition of palliative care, in order to provide clarity and education to healthcare practitioners and the public.

Strategy a. Review definitions developed and adopted by other state and national groups

Strategy b. Codify definition where appropriate

Strategy c. Facilitate cross-sector standardization of definition

Recommendation 2. Ensure that comprehensive and accurate information on palliative care is available to the public, health care providers, and health care facilities through the development and maintenance of a statewide Palliative Care Information and Education Program.

Strategy a. Create an online directory of palliative care resources.

Strategy b. Develop a communication plan to outreach to providers, patients, families, and caregivers

Strategy c. Plan a statewide conference focused on palliative care.

Recommendation 3. 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 assess the strengths, weaknesses, and needs of the palliative care workforce in Tennessee.

Strategy a. Research 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. Partner with other organizations interested in assessing the status of palliative care, including barriers to care, in Tennessee.

Strategy c. Encourage participation in the CAPC Mapping process to make it easier for patients, families, and providers to locate palliative care programs.

Appendices



State of Tennessee

PUBLIC CHAPTER NO. 955

HOUSE BILL NO. 2118

By Representatives Kumar, Weaver, Powell, Beck, Carter, Gilmore, Favors, Whitson,
Cooper, Thompson, Terry, Akbari, Camper, Moody, Turner

Substituted for: Senate Bill No. 2561

By Senators Hensley, Massey, Briggs, Crowe

AN ACT to amend Tennessee Code Annotated, Title 4, Chapter 29 and Title 71, Chapter 2, relative to palliative care.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF TENNESSEE:

SECTION 1. Tennessee Code Annotated, Section 4-29-244(a), is amended by adding the following as a new subdivision:

() State palliative care and quality of life council, created by § 71-2-115;

SECTION 2. Tennessee Code Annotated, Title 71, Chapter 2, Part 1, is amended by adding the following as a new section:

71-2-115.

(a) As used in this section:

(1) "Commission" means the Tennessee commission on aging and disability;

(2) "Council" means the state palliative care and quality of life council;

(3) "Executive director" shall mean the executive director of the Tennessee commission on aging and disability; and

(4) "Palliative care" means an approach that improves the quality of life of patients and their families facing the problems associated with chronic life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care includes, but is not limited to:

(A) Discussions involving a patient's goals for treatment;

(B) Discussions involving treatment options that are appropriate to the patient, including, where appropriate, hospice care; and

(C) Comprehensive pain and symptom management.

(b) The state palliative care and quality of life advisory council is established.

(c) The purpose of the council is to continually assess the current status of palliative care in the state and to review the barriers that exist that prevent such care from being obtained and utilized by the people who could benefit from such care. The council shall provide recommendations to the governor and to the general assembly on issues related to its work.

(d) The council membership shall be appointed by the executive director, after consulting with Tennessee Hospice Association, Tennessee Hospital Association, Tennessee Medical Association, Tennessee Nursing Association, Tennessee Health Care Association, Tennessee Association of Home Care, and the Tennessee Chapter of American Cancer Society, and shall include interdisciplinary palliative care medical,

HB 2118

nursing, social work, pharmacy, and spiritual professional expertise; patient and family caregiver advocate representation; and any other relevant appointees the executive director determines appropriate. The advisory council shall consist of no more than eleven (11) members. The executive director shall consider the racial, geographic, urban/rural, and economic diversity of the state when appointing members. Membership shall specifically include health professionals having palliative care work experience or expertise in palliative care delivery models in a variety of inpatient, outpatient, and community settings such as acute care, long-term care, and hospice, and with a variety of populations, including pediatric, youth, and adult. At least one (1) council member shall be a board-certified hospice and palliative medicine physician, at least one (1) council member shall be a licensed certified registered nurse practitioner with expertise in palliative care, and one (1) council member shall be from the department of health. Council members shall be appointed for a term of three (3) years. The members shall elect a chair and vice chair, whose duties shall be established by the council. The council shall fix a time and place for regular meetings and shall meet no less than twice yearly.

(e) Council members shall receive no compensation for their services or travel reimbursement for attending meetings.

(f) The council shall consult with and advise the executive director on matters related to the establishment, maintenance, and operation of palliative care initiatives in this state.

(g) The commission shall provide administrative support to the council.

(h) By January 15th of 2020, and by January 15 of each subsequent year, the advisory council shall submit a report to the general assembly that addresses barriers to palliative care access, analyzes service utilization data, and provides recommendations and best practices to address gaps in service.

SECTION 3. This act shall take effect upon becoming a law, the public welfare requiring

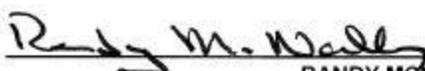
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HOUSE BILL NO. 2118

PASSED: April 24, 2018



BETH HARWELL, SPEAKER
HOUSE OF REPRESENTATIVES



RANDY MCNALLY
SPEAKER OF THE SENATE

APPROVED this 15th day of May 2018



BILL HASLAM, GOVERNOR

State Palliative Care and Quality of Life Task Force

- ∞ Created by the Tennessee General Assembly in 2017
- ∞ Diverse group of representatives from Tennessee's leading health care and community organizations, advocacy and professional associations, and consumers
- ∞ Met from September - December to discuss Tennessee's palliative care needs
- ∞ Submitted final report in January 2018



State Palliative Care and Quality of Life Advisory Council

- ∞ One of the Task Force's top recommendations
- ∞ April 2018, the General Assembly unanimously passed legislation
- ∞ Governor Haslam signed it into law on May 15, 2018
- ∞ Eleven (11) member Advisory Council
- ∞ Council members shall be appointed for a term of three (3) years.
- ∞ Solely advisory in nature
- ∞ *Report due each year to General Assembly*



Resources

- ∞ Palliative Care in TN Data mapped including locations, physicians, and GME
- ∞ State by State Review on Advisory Councils and Resulting Legislation
- ∞ CAPC State Palliative Care Forum for all palliative care champions working at the state to share
- ∞ National Academy for State Health Policy (NASHP) initiative to advance palliative care at the state level



Education & Outreach

- ∞ Honoring Choices Tennessee
 - Led by the Tennessee Department of Health
 - Outreach and Education for Advance Care Directives
- ∞ Other National Partners
 - National Patient Advocate Foundation
 - Common Practice / Hello Game



Advisory Councils and Resulting Legislation

Alabama

Code of Ala. § 22-5C

The State Advisory Council on Palliative Care and Quality of Life was created in 2015 with the following goals: three-fold: 1) establishes the Advisory Council, 2) requires the Authority to create a website containing palliative care information and resources in consult with the Council, and 3) establishes requirements for health facilities relating to palliative care. The Council meets quarterly. Information on previous and upcoming Council meetings, including agendas and minutes, are available.

Connecticut

SB 991/Public Act 13-55

Monthly meetings; however, no evidence of meetings after mid 2017

Requires the Department of Public Health to establish, within available appropriations, a Palliative Care Advisory Council to analyze the current state of palliative care in Connecticut; and advise the department on matters relating to the improvement of palliative care and the quality of life for persons with serious or chronic illnesses. The Commissioner of Public Health is also required to submit a report to the joint standing Committee on Public Health beginning on January 1, 2015, and annually thereafter, regarding the Palliative Care Advisory Council's recommendations.

Recommendations/ Annual Reports

[2016 Report](#)

[2015 report](#)

[2014 report](#)

Data Collection: Large focus on compiling “benchmark data” to see how CT compares to nation

Maryland

Health-General Article §§13601-13-1604.

The State Advisory Council on Quality Care at the End of Life was created in December 2002. The Council studies the impact of State statutes, regulations, and public policies on the providing of care to the dying. The Council monitors trends in the provision of care to patients with fatal illnesses and participates in public and professional educational efforts concerning the care of the dying. The Council also advises the General Assembly, Office of Attorney General, Department of Aging, and the Department of Health and Mental Hygiene matters related to the provision of care at the end of life.

[Report](#) with 37 best practices for palliative care programs in the state

Subcommittees

- [Advance Directive Subcommittee](#)
- [Obstacles to Implementation Subcommittee](#)
- [Public Education Subcommittee](#)
- [Review of Existing Legislation Subcommittee](#)
- [Underserved Populations Subcommittee](#)

Legislation: Strong legislative focus. Discuss specific bills, and weigh in on state legislation

Minnesota

Minnesota Statutes, section 144.059.

By law, the Council must assess the availability of palliative care in the state of Minnesota, analyze barriers to greater access to palliative care, and make recommendations for legislative action. By February 15 of each year, the Council is required to report on its progress. This report provides an introduction to palliative care, updates the status of the Council, provides preliminary reporting on the availability of palliative care in Minnesota, and outlines the Council’s next steps

Next Steps Over the course of the next year, the Council will focus on four main priorities for palliative care in Minnesota:

1. Define the long-term 2025 vision, or the “to be” state;
2. Document the gaps between the “as is” (2018) and “to be” state (2025);
3. Create a strategic plan to reduce the identified gaps between “as is” and “to be” states of palliative care. The strategic plan will include the goals, objectives, strategies required to successfully implement the long-term vision and fulfill its legislative mandate. The plan will include monthly deliverables through June, 2019, quarterly deliverables for July, 2019 through December, 2020, and annual deliverables for 2021 through 2025; and will be reviewed no less than annually; and
4. Determine the working infrastructure (e.g. by-laws) required for the Council to successfully achieve the legislative directives for and the long-term visions of the Palliative Care Advisory Council. The formation of a strategic plan will provide direction and guidance for the Council for the next year, and beyond. It will allow for the flexibility needed to respond to evolving changes within the Council membership, as well as in the legislative, medical and social communities.

Vermont

Act 25 of 2009. Sec. 2. 18 V.S.A. § 2

Led by the Vermont Ethics Network, the focus of the task force is to coordinate palliative care and pain management initiatives in Vermont through information sharing and network development; to help people to gain access to services; and to propose solutions for addressing gaps in services and educating consumers about their rights under the Patients’ Bill of Rights for Palliative Care and Pain Management.

Public Education: Established an educational website

Legislative: Expanded its 1115(a) waiver, to establish a Pediatric Palliative Care Program that offers services such as care coordination, family/caregiver training, and expressive therapies to

medically eligible children and adolescents up to the age of 21. This waiver was recently extended through 2021

Other State Legislation

New York

Requires physicians to offer information about palliative care to those newly diagnosed with a terminal illness and required facilities to adopt policies and procedures to provide patients with information about palliative care and to facilitate access to it. Department of Health published resources on its website regarding the laws and sent letter to administrators of facilities

Required Education: To newly diagnosed patients, materials developed at state level

Massachusetts

Requires licensed hospitals, skilled nursing facilities, health centers, and assisted living facilities to identify patients and residents who would benefit from PC and distribute information regarding its availability. Promulgated regulation to implement the law and developed a pamphlet translated into 9 languages to help facilities meet the obligation.

Required Education: To newly diagnosed patients, materials developed at state level

Oregon

Requires licensed hospitals, skilled nursing facilities, health centers, and assisted living facilities to identify patients and residents who would benefit from PXC and distribute information regarding its availability.

Required Education: To newly diagnosed patients

Colorado

Legislation specifying standards to facilities that provide PC. The standards require these programs to develop policies and procedures addressing how services such as assessment and management of pain and symptoms, goals of care and advance care planning, psychosocial and spiritual support, and other aspects of care will be provided and documented.

Legislation: Standards for facilities

California

CMS waiver to allow them to provide hospice and palliative care in concurrent with treatment to children enrolled in Medicaid

Mandates that all physicians and surgeons (with the exception of those practicing in pathology or radiology specialty areas) complete 12 hours of continuing education courses in pain management and the “treatment of terminally ill and dying patients.”

Data Collection: Tracks percentage of hospitals offering inpatient palliative care

South Carolina

For dual eligible, Medicaid plans are required to submit the number of eligible beneficiaries as well as those receiving palliative care services.

Legislative: testing a palliative care benefit for its dual-eligible population. Services will focus on pain management and comfort care, and plans will be required to report on the total number of eligible beneficiaries, as well as those receiving palliative care services.

List barriers identified by Council members

Organizational

- Provider
- Lack awareness
- Palliative Care vs. Hospice
- Concern PC will misrepresent prognosis
- Concern family will be offended / think provider is giving up
- Think PC offers limited hours / services or understaffed
- Optimistic view of disease trajectory and/or impact of illness
- Loss of autonomy
- Difficulty identifying when/who is appropriate to refer
- Cultural beliefs/values
- Patient/Family
- Lack awareness of service
- Palliative Care vs. Hospice
- Prefer to see their primary provider
- Concerns regarding additional cost, additional time,
- Optimistic view of disease trajectory and/or Impact of illness
- Avoidance of discussing prognosis/EOL issues – to shield patient or family
- Cultural beliefs/values of patient/family

Systematic (Outpatient, Inpatient, Healthcare)

- Inadequate funding/ reimbursement
- Payment Models
- Too few trained providers
- Too few programs
- Existing programs are overstretched, understaffed
- Lack of Standardization
- Fragmented healthcare system – ACP and established goals of care
- plans not continued in new level of care
- Palliative Care not available or funded in all settings (i.e. nursing homes)
- Can be difficult to quantify cost-savings and demonstrate overall financial value
- Still gaps in care/unmet needs (i.e., coverage of in-home caregivers)

Societal

- Disparities in Access
- Geography
- Diagnosis
- Prognosis
- Racial minorities less likely to utilize (due to overall less access to healthcare and/or cultural factors specific to EOL planning)
- Health literacy/Education level (more opt to use pc if have college degree)
- Age (younger less likely to utilize)
- If have dependent children – less likely to utilize
- Scope of services varies (may or have not have access to community-based care, residential program, supportive services; differences in frequency of visit)

This report was prepared by the Tennessee Commission on Aging and Disability.