Improving the Provision of Palliative Care in the Commonwealth

Joint Commission on Health Care
October 5, 2016 Meeting

Stephen Weiss
Senior Health Policy Analyst

Includes JCHC Member-Proposed Policy Option 4
Study Background

• Delegate Filler-Corn requested that the JCHC:
  — Study the delivery and corresponding regulations of palliative care in the Commonwealth
  — Evaluate the need for public education on palliative care
  — Determine if accessible statewide education resources exist for citizens

• The study was approved by the JCHC members during the May 26, 2016 work plan meeting.

• The study request is based on HB 473 (Delegates Filler-Corn, Krizek and Mason) which was introduced during the 2016 General Assembly session. As written, the bill amended § 32.1-127 and added § 32.1-371 and § 32.1-372 by:

  1) Requiring every hospital, nursing home, and licensed and certified nursing facility in the Commonwealth to establish a system for identifying patients or residents who may benefit from palliative care and provide information about and facilitate access to appropriate palliative care services for them;
  2) Creating a Palliative Care Consumer and Professional Education and Information Program within the Virginia Department of Health to maximize the effectiveness of palliative care initiatives in the Commonwealth and ensure that comprehensive and accurate information and education about palliative care is available to the public, health care providers, and health care facilities through the Department’s website; and
  3) Creating an eight member Palliative Care and Quality of Life Advisory Council to advise the Department on the establishment, operation, maintenance, and outcomes evaluations of palliative care information and education initiatives.

– HB 473 was continued to 2017 in House Health, Welfare and Institutions Committee
  • HB 473 had a fiscal impact statement of $120,506 per year. The impact includes the cost of the council ($10,000) and one professional to implement the education and information program and website ($110,506).
State and Federal Definitions of Palliative Care in Code

Palliative Care is defined in the Virginia Code and the Administrative Code within the Hospice Program licensing sections.

- Code of Virginia Article 7 - Hospice Program Licensing § 32.1-162.1.
  - “Palliative care" means treatment directed at controlling pain, relieving other symptoms, and focusing on the special needs of the patient and family as they experience the stress of the dying process, rather than the treatment aimed at investigation and intervention for the purpose of cure or prolongation of life.

- Administrative Code – 12VAC5-391-10.
  - Part I. Definitions and General Information. “Palliative care" means treatment directed at controlling pain, relieving other symptoms, and focusing on the special needs of the patient and family as they experience the stress of the dying process. Palliative care means treatment to enhance comfort and improve the quality of a patient's life during the last phase of his life.

In addition, the State Medicaid program considers Palliative Care to be a covered service for reimbursement based on federal law and regulations.

- Administrative Code – 12VAC30-50-270.
  - Hospice services (in accordance with § 1905 (o) of the Act). A. Covered hospice services shall be defined as those services allowed under the provisions of Medicare law and regulations as they relate to hospice benefits and as specified in 42 CFR Part 418.

The federal code of regulations defines Palliative Care as follows:

- 42 CFR § 418.3 Definitions. For purposes of this part - Attending physician
  - “Palliative care” means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.
## Palliative Care vs. Hospice Care: Similar but Different

“All Hospice Care is Palliative Care but not all Palliative Care is Hospice Care”

### Palliative Care
- Appropriate for patients in all disease stages; can accompany the patient from diagnosis to cure, death and/or bereavement for the family
- Uses life-prolonging, pain management and curative medications
- Focuses on relief from physical suffering; the patient may be being treated for a disease or may be living with a chronic disease, and may or may not be terminally ill
- Appropriate at any age, including for infants and children
- Addresses the patient’s physical, mental, social, and spiritual well-being
- Addresses and provides support for the family and care-giver, socially and emotionally
- Provides an interdisciplinary team of nurses, physicians, social workers, chaplains, counselors, and hospice aides to address the holistic needs of patients & families

### Hospice Care
- Does not use life-prolonging medications; expected prognosis of 6-months or less if the illness runs its normal course
- Makes the patient comfortable and prepares the patient and the patient’s family for the patient’s end of life when it is determined treatment for the illness will no longer be pursued
- Is offered at a place the patient prefers such as in their home, in a nursing home or occasionally in a hospital
- Provides all medications, medical equipment and supplies to the patient as needed or required
- Provides an interdisciplinary team of nurses, physicians, social workers, chaplains, counselors, and hospice aides to address the holistic needs of patients & families
- Provides bereavement services to families after death of the patient. Hospice is a comprehensive service provider not simply a visiting nurse service.

Source: Adopted from a CMS Infographics and the American Cancer Society Cancer Action Network Infographics.
Continuum of Illness and Provision of Palliative Care

- **Curative Care**
- **Palliative Care**
- **Hospice**
- **Death and Bereavement Care**

Diagnosis

Time

% focus

Best Care Possible
Background on Palliative Care

- Historically, palliative care has been associated with hospice care as a service provided to help comfort terminally ill patients and their families during the last stages of their lives.

- According to the National Hospice and Palliative Care Organization, the percentage of hospice patients covered by the Medicare hospice benefit versus other payment sources was 84.1% in 2011.

- To be eligible for Medicare's hospice benefit, a beneficiary must be certified by a physician to have a life expectancy of six months or less if the illness runs its natural course and the beneficiary must sign a statement electing the hospice benefit, which means ending all treatments to cure the illness and electing to receive only comfort care, referred to as palliative care (42 CFR 418 to 418.405).

Expanded Definition

- Today the definition of palliative care is being expanded beyond traditional hospice care; palliative care is now described to mean “comfort care” for a variety of long term, chronic and/or seriously ill patients as well as the traditional terminally ill.

- The goal is to apply palliative care to any illness or disease that requires a team approach to patient care, similar to a medical home.

- A palliative care team consists of health care providers, clergy and social service programs that provide an array of services to people, and their families, who are recovering from serious illnesses and diseases that were once considered terminal.
Background on Palliative Care - Demographics

The need for an expansion of palliative care into other areas of the health care field beyond hospice care involves the demographics of an aging population that includes people living longer due to the advancements in medical treatment.

The demographics for the aging population include the following:

- The National Center for Health Statistics reports that the average life expectancy in the United States went from 73.7 years in 1980 to 78.8 years in 2014, an increase of 5 years.
- According to the US Census Bureau, the number of people aged 65 and over is the fastest growing segment of the US population; 10,000 baby boomers will turn 65 each day from now until 2030.
- The two leading causes of death for those over age 65 are cardiovascular diseases and cancer; however:
  - Between 1980 and 2008 cancer death rates dropped by 15%; while the 5-year survival rate of a cancer patient increased from 49.1% to 68.9% during the same period.
  - Between 1980 and 2008 cardiovascular disease death rates dropped by 64%; the 5-year survival rate for people with heart failure increased by 45% from 1995 to 2004.

In addition, according to a 2011 report by the National Conference of State Legislatures and the AARP Public Policy Institute, 90% of those over age 65 want to age in place – at home in their communities.
## Population Growth: Total Compared to Aged from 2000 to 2010 Census

<table>
<thead>
<tr>
<th></th>
<th>2000</th>
<th>2010</th>
<th>Change</th>
<th>Percent Change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Virginia</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>7,078,515</td>
<td>8,001,024</td>
<td>922,509</td>
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<tr>
<td>65 and over</td>
<td>792,333</td>
<td>976,937</td>
<td>184,604</td>
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</tr>
<tr>
<td>85 and over</td>
<td>87,266</td>
<td>122,403</td>
<td>35,137</td>
<td>40.3%</td>
</tr>
<tr>
<td><strong>United States</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>281,421,906</td>
<td>308,745,538</td>
<td>27,323,632</td>
<td>9.7%</td>
</tr>
<tr>
<td>65 and over</td>
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<td>40,267,984</td>
<td>5,276,231</td>
<td>15.1%</td>
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<tr>
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<td>4,239,587</td>
<td>5,493,433</td>
<td>1,253,846</td>
<td>29.6%</td>
</tr>
</tbody>
</table>

Probability (%) of Developing Invasive Cancers by Age and Sex, US, 2008-2010 *

- 3.5% (Male) 6.8% (Female) Birth to 49
- 5.4% (Male) 6.0% (Female) 50 to 59
- 15.4% (Male) 10.1% (Female) 60 to 69
- 36.9% (Male) 26.7% (Female) 70+

Prevalence of Coronary Heart Disease by Age and Sex, US, 2009 - 2012

- 0.6% (Male) 0.6% (Female) 20 to 39
- 6.3% (Male) 5.6% (Female) 40 to 59
- 19.9% (Male) 18.8% (Female) 60 to 69
- 32.2% (Male) 18.5% (Female) 70+

*For those who are cancer-free at the beginning of each age interval. †All sites excludes basal cell and squamous cell skin cancers and in situ cancers except urinary bladder.

Source: American Heart Association
Chart I: Age-Adjusted Death Rates for Cancer

Chart II: Age-Adjusted Death Rates for Cardiovascular Diseases

Sources
The American Heart Association (AHA) recently released a policy paper with recommendations specifically on the importance of palliative care for patients with advanced cardiovascular disease and their families.

The AHA paper discusses the following issues:

- Palliative care is important as a way to improve communications between patients, their families and health care providers as well as improve the quality of life for patients with advanced cardiovascular disease which can reduce symptoms and improve patient outcomes.
- A lack of education and awareness about palliative care may make providers uncomfortable and avoid discussions about the services with their patient.
- Providers may not be aware of the availability of palliative care services in their setting or community.
- Providers may be concerned that the patient or family member will misunderstand the palliative care program and assume that the provider may want to discontinue curative or life-prolonging treatment.
- Patients and their families might not think the services are covered because palliative care is often equated with hospice.
The pressure on hospitals and health care providers to adopt other methods of working with patients is being driven by Medicare payment policy.

Under current Medicare rules (42 CFR part 412) hospitals are being penalized through reduced payments for excessive preventable readmissions as part of a “Hospital Readmissions Reduction Program”

The penalties are applied to:

- heart attack, heart failure
- pneumonia
- chronic obstructive pulmonary disease (COPD)
- elective hip or knee replacement

Any readmission for any cause, other than scheduled procedures, counts as a readmission if it occurs within 30 days of the patient’s discharge.

In Virginia, 41 hospitals were penalized for excessive preventable readmissions for patients discharged with a diagnosis of either a heart attack or heart failure.

Palliative care for cardiovascular disease patients is a program designed to target a patient’s quality of life and improve treatment outcomes which may prevent hospital readmissions, thus avoiding payment penalties.
Cancer Treatment and Palliative Care

- The American Cancer Society (ACS) has long been a proponent of palliative care for cancer patients and survivors.

- A variety of studies indicate that palliative care provided early in the diagnosis stage along with treatment reduces symptoms, improves the patient’s quality of life and increases patient survival time.

- Different studies done at hospitals across the country suggest that per admission savings from palliative care programs for cancer patients ranges from $2,600 to $7,000, or more; the studies compared the services provided to similarly ill patients who either received or did not receive palliative care as part of their treatment regimen.

- The decrease in costs “consistently occurred 48 hours after a palliative care team consultation — no matter when the consultation occurred—and no corresponding decline was observed in the usual care group at any point during their hospital stay” due to better and more involved decision making by patients, their families and health care providers related to treatment.

- The savings were found in laboratory, pharmacy and intensive care unit services for patients discharged alive after admission; and for patients who died in the hospital after admission.

- The 2008 study indicates that much of the savings for patients discharged alive were attributed to better pain management and quality of life issues while the savings from those patients that died were attributed to more acceptable decision making between patients, family members and providers resulting in the avoidance of unnecessary, and often unwanted, procedures.

- ACS research indicates that in spite of the success of the program, 7 out of 10 consumers do not know about palliative care and clinicians misunderstand it.

Recognizing the changes brought on by the aging population and in an attempt to improve care and treatment for people with long term illnesses, CMS began a pilot program in 2015 to allow patients in selected hospice care settings to elect to continue curative care and treatment while also receiving the full range and scope of palliative care services.

The program, Medicare Care Choices Model, is available to Medicare recipients and Medicare-Medicaid recipients.

Five hospice providers in Virginia were chosen to participate in the Choices program:
- Capital Caring, Falls Church
- Mountain Valley Hospice and Palliative Care, Hillsville
- Carilion Clinic Hospice Service of Roanoke
- Carilion Clinic Hospice of Franklin, Rocky Mount
- Carilion Clinic Hospice Service of New River Valley, Radford

Palliative care in these programs include the involvement of nurses, social workers, hospice aides, hospice homemakers, volunteers, chaplains, as well as bereavement, nutritional support, and respite care services.

Duke University ‘Secret Shopper’ Program and Palliative Care

- In a ‘secret shopper’ study using an anonymous caller posing as a liver cancer patient, researchers at the Duke Cancer Institute found that most of the nation’s comprehensive cancer centers did not provide complete information about supportive services 38% of the time when asked whether palliative care was available.

- The study also found that in about 10% of the calls the potential patient was unable to confirm that palliative care was offered at all.

- In some instances, for answers other than "yes" as to whether palliative care was offered, the cancer center staff responded that:
  - palliative care was for end-of-life patients only;
  - no physicians specialized in symptom management; and/or
  - a medical record review would be needed first.

- In addition, there were some situations where the cancer center staff said that they were unsure if palliative care was available or that they were unfamiliar with the term.

- Approximately 37% of patients who called the cancer center were given correct information about the availability of palliative care.

- Callers who received a "yes" response were typically referred to patient navigation and genetic assessment services.

Sources
"Mystery shopper" study finds barriers to accessing palliative care services at major cancer centers [press release]. Alexandria, VA: American Society of Clinical Oncology; September 6, 2016.

Challenges to Providing Palliative Care Today Outside of Hospice

- In 2014, the Health Information Network (HIN) did a survey of 223 health care providers (hospitals, physicians, etc.) concerning palliative care. According to the results, 70% of the survey respondents have a palliative care program and over half of those that do not intend to launch one

- 51.6% of respondents indicated that timely referrals of patients to palliative care is the first and most sensitive of steps

- 78% of the survey respondents indicated that physicians are the primary identifiers of patients that might benefit from palliative care

- In spite of the physician’s role, 48% of survey respondents indicated that physician resistance is a key challenge to implementing a palliative care program

- The survey found that 93% of the patients in a palliative care program are in need of pain/symptom management

- 80% responded that patient/caregiver education was a key component of the program

- 88% of the survey respondents reported that patient satisfaction levels increased among Medicare patients in a palliative care program; with 89% reporting that caregiver satisfaction increased as well

- Finally, 70% of the survey respondents said that the palliative care programs they administer help curb healthcare utilization costs

Virginia
Billing and Reimbursement for Palliative Care

- The following slides provide an indication of the amount of reimbursement and billing that is occurring from hospitals and other facilities for palliative care in the Commonwealth. Palliative care patients were identified using the ICD-9 diagnosis code V66.7 and Z51.5 and Q5001 – Q5004. The information is provided by payer, age and type of discharge or transfer.

- The data was obtained for hospitals from VHI; and for hospitals and other providers from the Department of Medical Assistance (DMAS).

- VHI data includes all billing to hospitals from all payers, including DMAS. Eighty-three (83) hospitals submitted charges for palliative care during a 12-month period ending with the 3rd quarter of 2015.

- The DMAS payments include fee-for-service payments to all providers in 2015.

- Patients identified with these diagnosis codes can be receiving the hospice benefit, meaning they are within 6 months of dying and are no longer receiving curative treatment, or they can be receiving palliative care service without the hospice benefit as part of their treatment plan.

- The code is also a secondary code and may be under-reported.
Note: The VHI bill charge data was converted to payments using a 2-year average payment-allowance-from-charges by hospital by payer. The allowance from charges data was provided by VHI.
VHI Hospital Data

Number of Patients Per Payer, 12 month Period Ending 3rd Qrt 2015 for Palliative Care Diagnosis Code v66.7

- Medicare: 70.4%
- Medicaid: 5.7%
- Insurance/Third Party: 22.2%
- Self Pay: 1.7%

Source: VHI Data Run
Total = 23,486 patients, 97.9% of all patients with the palliative care diagnosis code

Age Groups for Hospital Patients, 12 month Period Ending 3rd Qrt 2015 with Palliative Care Diagnosis Code v66.7

- Age Group 0-18: 0.6%
- Age Group 65+: 74.9%
- Age Group 19-65: 24.4%

Source: VHI data run
Total = 23,990 patients

Discharge/Transfer Status of Hospital Patients, 12 month Period Ending 3rd Qrt 2015 with Palliative Care Diagnosis Code v66.7

- Death: 45.6%
- Hospice-home: 20.9%
- Hospice-Medical Facility: 11.9%
- Other: 2.9%
- Home/Self Care: 4.3%
- Skilled nursing facility: 10.3%
- To home under care of home health: 4.1%

Source: VHI data run
Total = 23,990 patients
DMAS Fee-for-Service (FFS) Payment Data

**DMAS Payments in 2015**
- Palliative Care Diagnosis Code v66.7

**Age Groups for DMAS Patients in 2015**
- with Palliative Care Diagnosis Code v66.7

**Percent Reimbursed by Age Groups for DMAS Patients in the Hospital Setting in 2015**
- with Palliative Care Diagnosis Code v66.7

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Number of Patients</th>
<th>% of Total Age Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age Group 0 - 18</td>
<td>28</td>
<td>12.33%</td>
</tr>
<tr>
<td>Age Group 19-65</td>
<td>82</td>
<td>36.12%</td>
</tr>
<tr>
<td>Age Group 66+</td>
<td>117</td>
<td>51.54%</td>
</tr>
<tr>
<td>Total Hospital</td>
<td>227</td>
<td></td>
</tr>
</tbody>
</table>

Total hospital reimbursements were $21 million.

227 patients, or 21% of the total number of FFS patients with the palliative care diagnosis code (1,076), were responsible for 87% of the total FFS reimbursements in 2015.
Stakeholder Observations in Virginia

- In speaking to stakeholders across the state, including medical directors of palliative care programs, hospice workers, palliative care program directors and providers, the conversations and observations about palliative care outside of hospice are similar to the findings reported in the HIN survey.

- The medical directors and professors of palliative care programs at Eastern Virginia Medical School, the University of Virginia, and VCU all indicate that medical schools need to do a more complete job of educating medical students about palliative care.

- All three indicated that the amount of time spent in the classroom or other environments where medical students are in training is insufficient to teach them how to talk to patients and family members about palliative care, death, and/or dying.

- The nurse director of one palliative care program said family members and patients are often angry and confused when they enter the palliative care unit at the hospital. For them the term palliative care is associated with hospice and there is an assumption that curative treatments have ended. The director also indicated that when the program started in 2009 it took some time for the oncology physicians to support the program, viewing it as duplicative of the work they thought they were doing.
Stakeholder Observations in Virginia

• According to the medical directors at UVA and VCU, many of their palliative care patients drive long distances for services
  
  • For UVA, 40% of cancer patients travel more than an hour to receive their care; many patients ask why they cannot get some services closer to home
  • In most cases reimbursements are the issue, but if providers can be found, financial arrangements between the programs may be arranged

• All of the stakeholders agreed that a statewide council that includes all facets of palliative care would be helpful in defining what:
  
  • a good palliative program should include
  • information can be most beneficial to the general public
  • information and educational material may be most helpful to providers

• Stakeholders also mentioned that the council should be more inclusive of all providers and represent all interests in palliative care – including long-term care, hospice providers and nutritionists
Stakeholder Observations in Virginia – Website and Provider Portal

- The stakeholders were unanimous that a website that included information on palliative care for medical professionals and the general public would also be beneficial.

- Many of the stakeholders expressed a strong interest and desire to have a separate and secure web-portal for providers included on the website.
  
  - The portal may include a directory distinctly identifying community providers, hospital providers, physicians and hospice providers around the state that could be contacted by providers for assistance in forming a palliative care team for patients and their families.

  - A separate portal will allow hospitals and physicians to work with each other on sensitive patient issues that may include financing of services.
Stakeholder Observations in Virginia – Website and Provider Portal

- All of the stakeholders reported that they have a difficult time locating community providers for assistance with palliative care
- The lack of information inhibits their program’s ability to have beneficial and useful community and outpatient programs
- A neutral website that can be a clearinghouse for educational material, with palliative care provider directories dedicated to Virginia, is something the stakeholders agreed is a necessity
- The material included on the website should be determined by a council
It is difficult to find palliative care providers for people whose illnesses and disease states do not fall within the hospice definition of ending curative treatment.

The medical director of a large palliative care program in Northern Virginia said finding providers is labor intensive.

Palliative care providers do not have to be certified to be members of an organization and not all certified physicians are members of the various organization where provider directories or lists might be found.

A review of the different websites for Virginia found that the material on one website may or may not match the information on another.

For example, 30 of the 46 certified palliative care hospitals match between the Get Palliative Care and American Council on Surgeons cancer certified sites.

<table>
<thead>
<tr>
<th>Websites</th>
<th>Number of Hospitals / Providers Listed</th>
<th>Number of Cities</th>
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</thead>
<tbody>
<tr>
<td>Getpalliativecare.org</td>
<td>35</td>
<td>26</td>
</tr>
<tr>
<td>National Hospice and Palliative Care Organization *</td>
<td>13</td>
<td>10</td>
</tr>
<tr>
<td>American Council on Surgeons Commission on Cancer *</td>
<td>46</td>
<td>39</td>
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<table>
<thead>
<tr>
<th>Physicians</th>
<th>Number of Physicians / Nurses Listed</th>
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<tbody>
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<tr>
<td>American Board of Family Medicine</td>
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<tr>
<td>American Board of Medical Specialists</td>
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<td>38</td>
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<tr>
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<tr>
<td>Advanced Certified Hospice and Palliative Nurses (ACHPN)</td>
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</tr>
<tr>
<td>Certified Hospice Medical Director</td>
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</table>

The National Hospice and Palliative Care Organization website lists both palliative care specific providers and hospice provider. The only way to know if any of the hospice providers are also offering palliative care services is to follow additional detail links for each hospice provider.

The American Council on Surgeons website lists 38 Commission on Cancer certified hospitals but combines several hospitals into one even though the hospitals are in different locations.

Comments by Medical Educators in Palliative Care

**Virginia Commonwealth University**
Danielle Noreika, MD, FACP
Medical Director, Inpatient Palliative Care Services; Assistant Professor of Medicine

There is one required lecture for fourth year medical students and an option to do an elective in palliative care as both a third year and fourth year medical student.

There are also a short series of courses for second year medical students that touch on palliative care broadly along with other topics such as humanities, ethics, etc. Palliative Care training is limited but the students are exposed to it along with hospice care during their medical education.

There needs to be more incorporation of palliative training into medical school education.

Learning how to manage symptoms, how to work with an interdisciplinary team to improve patient care, and how to talk with patients and families about difficult medical situations are tools that can apply to just about any field of medicine.

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**Eastern Virginia Medical School**
Marissa C. Galicia-Castillo, MD, MSeD, CMD, FACP, AGSF, FAAHMP; Professor of Geriatrics; Section Head, Palliative Medicine; Glennan Center for Geriatrics and Gerontology

Third year medical students are required to take six 8-week “clerkships”. There is a mandatory Palliative Medicine session that is 2 hours long in each clerkship, for a total of 6 sessions or 12 hours total per student.

These programs are done in large group settings (approximately 150 students);

There is no formal education on how to work with a dying patient and their family. For most medical students this part of the knowledge base comes from on-the-job training.

The only time palliative care is integrated into training is if students choose to do a one-day observational experience through geriatrics. This consists of 3-5 students within a group of about 20 students.

Finally, some medical students will choose to do 4th year elective in palliative care (approximately 3-4 out of 146 students).

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**University of Virginia**
Leslie J. Blackhall, MD
Associate Professor of Internal Medicine, General Medicine, Geriatrics and Palliative Care

First year: overview of palliative care and end of life issues for patients with common life-limiting illnesses and some case studies scattered throughout the year.

3rd year students receive 1.5 hour workshop with nursing students using standardized patient on communications issues in end of life care.

4th year students receive 1-2 days with a palliative care as part of the geriatrics clerkship.

Students can choose to do electives during 4th year as well.

The education on palliative care is minimal and similar to the other universities.
Virginia Hospital and Healthcare Association  
Palliative Care Forum in Virginia

- The Virginia Hospital and Healthcare Association (VHHA) has a palliative care forum with approximately 40 members
- The forum was established by VHHA to assist member organizations in strengthening their palliative care programs
- The forum was established in 2011 and includes the Virginia Association for Hospices & Palliative Care, Honoring Choices, The Physician Orders for Scope of Treatment Group and other community groups
- The forum meets 4 times a year with approximately 10 – 15 people in attendance in any given meeting
- According to VHHA, palliative care is a part of the overall issues related to advanced care planning
  - Advanced care planning is a way to allow patients and families to express their desires for care when they have an advanced illness
- The forum’s goals are to:
  1. “Provide an opportunity for providers to collaborate and discuss how best to meet the growing needs in our communities for palliative care services across the full continuum of care.
  2. Develop and support a statewide network for sharing information and best practice strategies for creating optimal palliative care programs to improve end of life care including outpatient programs.
  3. Support the training, education and practice strategies that create an optimal patient and family experience when receiving palliative care in hospitals, health care systems and the community.
  4. Support the efforts of the Physician Order for Scope of Treatment (POST) program.
  5. Assist in the education of physicians regarding coding and palliative care.
  6. Support the credentialing for all palliative care team members.” *

Other States and Palliative Care

Nine states that have passed laws forming a palliative care advisory council.

- Of the 9 states, 4 specifically mentioned the creation of a website and/or the use of the state agency website already in existence to disseminate information to the public and providers.

- The mission of each state council is to educate the public and providers about palliative care, identify best practices, develop education material and continuing education opportunities for health care providers.

- Unlike the other states, the Maryland Health Care Commission is required to establish at least 5 palliative care pilot programs and use the programs to identify data, cost savings, access to health care for patients, develop standards for palliative care programs and identify core measures for data collection.

- Most of the states require formal reports on the status of the council’s work.

- Funding for the councils is not identified in the statutes but some of the councils are permitted to accept gifts and donations as part of their operating budgets.
## Nine States Identified with Palliative Care Councils

<table>
<thead>
<tr>
<th>State</th>
<th>Number of Members</th>
<th>Website Required</th>
<th>Agency Where Council is Located</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alabama</td>
<td>Not Specified</td>
<td>Yes</td>
<td>State Health Department</td>
</tr>
<tr>
<td>Connecticut</td>
<td>13</td>
<td>*</td>
<td>Department of Public Health</td>
</tr>
<tr>
<td>Maine</td>
<td>13</td>
<td>Yes</td>
<td>Independent; advises Maine Center for Disease Control and Prevention within Department of Health and Human Services</td>
</tr>
<tr>
<td>Maryland</td>
<td>n/a</td>
<td>*</td>
<td>The Maryland Health Care Commission is an independent state agency located within the Department of Health and Mental Hygiene. Maryland will fund at least 5 palliative care pilot programs.</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>13</td>
<td>*</td>
<td>Department of Public Health under the Health and Human Services</td>
</tr>
<tr>
<td>New Hampshire</td>
<td>13</td>
<td>*</td>
<td>Department of Health and Human Services – Umbrella agency for health and human services</td>
</tr>
<tr>
<td>Oklahoma</td>
<td>8</td>
<td>*</td>
<td>Department of Health – Home Care, Hospice And Palliative Care Advisory Council</td>
</tr>
<tr>
<td>Oregon</td>
<td>9</td>
<td>Yes</td>
<td>Oregon Health Authority includes most of the state’s health care programs, including Public Health, the Oregon Health Plan, Healthy Kids, employee benefits and public-private partnerships.</td>
</tr>
<tr>
<td>Rhode Island</td>
<td>9</td>
<td>Yes</td>
<td>Department of Health</td>
</tr>
</tbody>
</table>

* Not explicitly mentioned in the state’s statutes or code.
Conclusion

• Based on the material reviewed for this study and information obtained from various stakeholders across the Commonwealth, there is a need for both a statewide advisory council and a website to act as a clearinghouse for information and educational material for both the general public and health care providers.

• The language in HB 473 that amends § 32.1-127 of the Virginia Code that requires every licensed hospital, nursing home and certified nursing facility to identify patients and residents who may benefit from palliative care services and to provide them with information; however, may be premature for the following reasons:

  — Information provided in this presentation from the various website directories and obtained during stakeholder conversations indicates that there is a lack of knowledge and uncertainty over the number and location of palliative care providers in the Commonwealth.

  — Implementation of this section of the legislation will be difficult to achieve because stakeholder discussions indicate that palliative care services are not easily identified in communities where the patients live and may not currently exist.

• Finally, locating the Palliative Care and Quality of Life Advisory Council within the Virginia Department of Health may be the best option although other options may be considered.

• Palliative care services are often confused with hospice services. Many of the current inpatient hospital palliative care programs are part of oncology departments; as a result, there is already built in confusion over what palliative care is and which patients will benefit most from the services.

• Stakeholder conversations suggest that placing the Council and website under a neutrally named state agency may be the most beneficial for the general public and providers.
Budget Impact

- Under HB 473, a Palliative Care and Quality Of Life Advisory Council was created within the Virginia Department of Health.

- The department estimated the cost for travel reimbursements, staff and the creation and maintenance of a website would be $120,506 per year.

- The impact included the cost of the council, $10,000 and $110,506 for one professional to implement the education and information program and website.

- There are two entities within the Commonwealth that may function similar to a Palliative Care Council, both are part of the Division of Legislative Services:
  
  - The Virginia Autism Advisory Council (§ 30-326 of the Virginia Code), whose mission is to define needed skill competencies and to advance higher education, training and educational opportunities for personnel and caregivers supporting individuals with autism. The Council also maintains a website as a clearinghouse of information on regarding autism in Virginia. The council has a sunset date of July 1, 2018. This Council is staffed by DLS and has an appropriation of $6,478.
  
  - The Virginia Freedom of Information Advisory Council (§ 30-179 of the Virginia Code), whose mission is to encourage and facilitate compliance with the Virginia Freedom of Information Act (FOIA). The Council provides advisory opinions concerning FOIA upon request, conducts training seminars and educational programs and publishes educational materials. The Council also maintains a website. This council is also staffed by DLS with 1.5 FTE dedicated to it and an appropriation of $203,746.
# Recommendations for House Bill 473

1. Change House Bill 473 by removing the amendment to section §32.1-127 of the Virginia Code that requires licensed hospitals, nursing homes and certified nursing facilities to identify and educate patients on palliative care services and continue the legislation that creates the advisory council and website by adding Title §32.1 -371 and §32.1-372 to the Virginia Code as originally written.

2. Change House Bill 473 by removing the amendment to section §32.1-127 of the Virginia Code that requires licensed hospitals, nursing homes and certified nursing facilities to identify and educate patients on palliative care services and continue the legislation that creates the advisory council and website by adding Title §32.1 -371 and §32.1-372 to the Virginia Code with language that expands the Palliative Care and Quality of Life Advisory Council within the Virginia Department of Health from eight to thirteen by adding a hospice provider, nutritionist, hospital administrator and nursing home and certified nursing facility.
## POLICY OPTIONS

<table>
<thead>
<tr>
<th>Option 1: Take no action.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Option 2: Introduce a budget amendment (language and funding) to provide $120,506 to the Virginia Department of Health for the creation of a thirteen member Palliative Care and Quality of Life Advisory Council within the VDH. The funds will be used to staff the Council and create a website.</td>
</tr>
<tr>
<td>Option 3: Introduce legislation to amend § 32.1-162.1 of the Virginia Code to add a separate definition of palliative care that incorporates the current service delivery system. The added definition may read as follows:</td>
</tr>
<tr>
<td>-- “Palliative care” means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice. (Source: 42 CFR § 418.3)</td>
</tr>
<tr>
<td>Additional Member-Proposed Policy Option 4: Add a section to Title §32.1 of the Virginia Code requiring the Virginia Department of Health to create a website for palliative care information.</td>
</tr>
</tbody>
</table>
Public Comments

Written public comments on the proposed options may be submitted to JCHC by close of business on November 2, 2016.

Comments may be submitted via:
- E-mail: jchcpubliccomments@jchc.virginia.gov
- Fax: 804-786-5538
- Mail: Joint Commission on Health Care
  P.O. Box 1322
  Richmond, Virginia 23218

Comments will be provided to Commission members and summarized and presented during JCHC’s November 9th meeting.

(All public comments are subject to FOIA release of records)