Palliative Care in Florida

Challenges and Options for Florida's Future

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Florida TaxWatch

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Senator Pat Neal
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Dear Fellow Taxpayer,

Providing quality and affordable long-term care for patients with serious and/or chronic conditions is a balancing act between risk and reward, including considerations of likely outcomes, comfort, quality of life, and cost. Elements involved in providing such adequate and affordable care include preventative services, acute or curative interventions, and long-term treatment plans preferably focused on an individual patient's unique needs. Against a backdrop of large-scale, institutionally based, intensive, acute "sick" care treatment for such patients with serious and/or chronic conditions, palliative care is emerging as a patient-focused, "less is more" practice that is generating improvements in the quality of life for patients while reducing healthcare costs.

Palliative care is an emerging and important part of the care spectrum. Multiple studies have shown that palliative care can improve patient quality of life while reducing overall healthcare costs. If properly expanded and administered, palliative care could help 'bend the cost curve' for patients, taxpayers, and the system as a whole.

Palliative care is similar in concept to hospice care, although hospice care is a more widely known and a more comprehensive form of care. Essentially, palliative care is an upstream form of care that can be provided earlier in the disease trajectory before the broader services of hospice care are needed. Palliative care is not a substitute or alternative for hospice care but can be an important part of disease management until the more comprehensive hospice care services are appropriate (and a patient becomes eligible). One side-note of our research was the realization that many patients – whether receiving palliative care services or not – wait too long to receive hospice care, which would have provided notable benefits if sought earlier.

There is a growing consensus that the frontier of palliative care is outpatient settings. Expansion of these services in community- and home-based environments may more efficiently meet the needs of the growing number of patients who would benefit from palliative care services.

This report, part of a series of TaxWatch research reports on long-term care, focuses on the benefits of palliative care and opportunities to increase use of these services in Florida. From our research, it is clear that community-based palliative care warrants special attention as a distinct and promising healthcare service. TaxWatch is pleased to present this research report so that the innovative means and benefits of palliative care can be better understood and leveraged by policymakers, providers, and patients alike.

Sincerely,

Dominic M. Calabro

Dominic M. Calabro
President & CEO

Introduction

At the conceptual level, palliative care is the management of the physical, psychological, spiritual, and social needs of patients, most often patients with nonterminal chronic or serious conditions (e.g., patients with cancer or diabetes that are expected to live for more than twelve months). Palliative care services are not curative but help patients manage the disease and their treatment to improve their overall functionality while providing relief from symptoms, such as the reduction of pain and suffering, and reducing stress for patients and their families. The underlying goal is to provide coordinated services that improve the patient's life – essentially to provide the right care at the right time for each patient given their condition and situation. The additional benefit of this highly individualized care, as studies have shown, is an overall reduction in treatment costs.

Defining palliative care specifically – in statute, for example – is somewhat more challenging. There is not a single definition and Florida statues do not currently provide one. One (of many possible) good explanatory definition comes from academic experts in a 2017 study of palliative care published in the peer-reviewed journal *Health Affairs*:

> *"Palliative care is a team-based specialty that focuses on improving the quality of life and relieving the suffering of people living with serious illness, as well as their families. Provided by doctors, nurses, social workers, and chaplains, specialist-level palliative care treats pain and other distressing symptoms, helps patients and families understand their illness and treatment options, matches treatments to their informed goals, and coordinates care across settings."* [1]

The closest thing to a state-sanctioned definition is provided by the *Florida Department of Health's Palliative Care Ad Hoc Committee*, which presented its report to the Surgeon General of the Florida Department of Health on June 30, 2016. For the purpose of the Committee's survey of palliative care programs in Florida, the Committee provided the following definition: Palliative care is "an organized service that sees patients, identifies needs, makes treatment recommendations, facilitates patient and/or family decision making, and/or directly provides palliative care to patients with a serious illness and/or their families." [2]

Generally, although not exclusively, palliative care is appropriate for patients with chronic diseases. "Chronic diseases are defined broadly as conditions that last 1 year or more and require ongoing medical attention or limit activities of daily living or both." [3] The most common such diseases (often interchangeably called "chronic conditions") are heart disease, cancer, chronic lung disease, stroke, Alzheimer's disease, diabetes, and chronic kidney disease.[4]

While "palliative care" can include lots of different types of services (which is part of the reason providing a specific definition is difficult), these services can be delivered by and in a variety of venues. The most predominant points of access in the United States are hospitals, which generally provide "inpatient" and/or "outpatient" palliative services, and hospices, which often offer both "inpatient" and "community/home-based" palliative care services for patients. (In this case, "points of access" means the "medical home" or broadly the physical location from which the treatment plan is coordinated and overseen.)

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[1] Diane Meier, Anthony Back, Amy Berman, Susan Block, Janet Corrigan, and R. Sean Morrison, "A National Strategy for Palliative Care," Health Affairs, 36:7; 1265-1273, 1266 (July 2017).

[2] Palliative Care in Florida: A Report to the Surgeon General of the Florida Department of Health by the Palliative Care Ad Hoc Committee. June 2016. Available at: https://issuu.com/floridahealth/docs/palliative_care_in_florida__2016.

[3] U.S. Centers for Disease Control and Prevention "About Chronic Diseases" (website) www.cdc.gov/chronicdisease/about/index.htm (last accessed January 25, 2019).

[4] See, e.g., U.S. Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), "Chronic Diseases in America" (website), www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm (last accessed January 25, 2019).

The Florida Department of Health's *Palliative Care Ad Hoc Committee* provides a definition of the three types of palliative care provision (for the purpose of the survey conducted by the Committee)—Inpatient, Outpatient, and Community/home-based:

- "Inpatient services were defined as an organized service that directly provides palliative care to hospitalized patients;
- Outpatient services were defined as an organized service that delivers palliative care to patients who are not hospitalized overnight but visit a hospital, clinic, or facility for diagnosis or treatment;
- Community/home-based services were defined as an organized service that provides palliative care to patients in their private residences, assisted living facilities, nursing homes, or wherever patients reside." [5]

It is important to examine the similarities, differences, and interactions between palliative care and hospice care. Although "hospice care" and "palliative care" are different services, there are many overlapping concepts – both hospice and palliative care provide patient-centered services aimed at delivering the right care at the right time for individual patients – and many of the services provided and the professionals involved are the same, and hospice providers are often palliative care providers as well. In fact, along with hospitals, hospice organizations are the most common types of palliative care service providers.

> *"Considered the model for quality compassionate care for people facing a life-limiting illness, hospice provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's family as well. Hospice focuses on caring, not curing. In most cases, care is provided in the patient's home but may also be provided in freestanding hospice facilities, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients with any terminal illness or of any age, religion, or race."* [6]

Like palliative care, hospice services are not limited to any age or type of diagnosis;[7] however, hospice care is provided when patients meet specified criteria related to medical prognosis. In Florida, hospice care is available for patients when the prognosis for life expectancy is one year or less, [8] although the (federal) Medicare hospice benefit provides hospice services through Medicare for patients when the prognosis is six months or less if the illness runs its normal course, and importantly, hospice care can be provided for an unlimited amount of time if the person continuously meets criteria. In this way, as well as others, Florida is a national leader and among the states looked to for best practices in compassionate care because of the importance of early referral to hospice care, which can actually increase life expectancy as well as improve the patient's quality of life and reduce overall healthcare costs.

Sometimes confusing the issue is that while hospice care is often considered to be "end of life care," hospice can be appropriate for many months for eligible terminally ill patients and early referral to hospice care can provide the right care at the right time for eligible patients.

Furthermore, referral to or receipt of hospice services neither means that a patient will soon die nor that the patient can only be served for a limited amount of time.

> *"Receiving hospice care does not mean giving up hope or that death is imminent. The earlier an individual receives hospice care, the more opportunity there is to stabilize your medical condition and address other needs. Some patients actually improve and may be discharged from hospice care."* [9]

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[5] Palliative Care in Florida: A Report to the Surgeon General of the Florida Department of Health by the Palliative Care Ad Hoc Committee. June 2016.

[6] National Hospice and Palliative Care Organization, "Facts and Figures: Hospice Care in America. 2017 Edition (Revised April 2018).

[7] Approximately one in 7 Florida hospice patients in 2016 were under 65 years old. Florida Department of Elder Affairs, "Hospice Demographic and Outcome Measures: 2017 Report."

[8] Section 400.601, Florida Statutes (2018), defines terminally ill patients as those whose life expectancy is one year or less if their illness runs its normal course.

[9] "Hospice Myths & Facts" website, Florida Hospice & Palliative Care Association, accessed on October 31, 2018, available at: https://www.floridahospices.org/hospice-palliative-care/about-hospice/hospice-myths-facts/

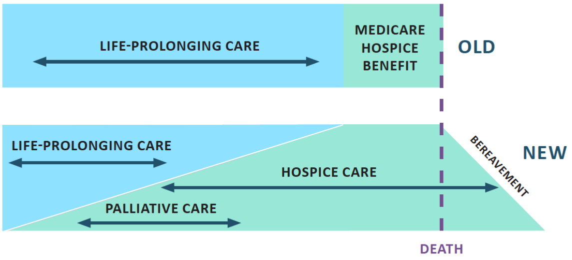
In fact, more than one in six patients discharged from Florida hospice care in 2016 were cases where the patient was still alive when hospice care services were ceased.[10]

Likewise, Medicare and "most private insurance pays for hospice care as long as the patient continues to meet the criteria necessary. Patients may come on and off hospice care, and re-enroll in hospice care, as needed."[11]

Both hospice and palliative care use an interdisciplinary team of specialists to provide unique, person-centered services. Either hospice or palliative care may be the most appropriate care for an individual beginning at diagnosis, although hospice care provides additional benefits that are not part of palliative care that are unique and important for terminally ill patients, such as advanced care planning, medications, supplies, and medical equipment, to name a few. The ideal interaction between palliative care and hospice, depending on the patient's age and condition, is a near-seamless transition from palliative services to hospice services based on the patient's prognosis. Palliative care cannot and should not replace or substitute hospice care and should not delay the provision of hospice care for eligible and appropriate terminally ill patients, but palliative care can serve both to provide services for those patients with chronic but not terminal conditions and to serve a patient's needs until hospice care is appropriate.

Historically, "medical care" beginning at diagnosis focused predominantly on curative treatments or "life prolonging" care, up to a point where hospice care services took over to provide such elements as pain and symptom management. Now, often beginning with diagnosis of a serious illness and concurrent with life-prolonging care, palliative care services are provided to the patient and work in conjunction with the curative treatment until (or unless) hospice services are appropriate for the patient. Both hospice and palliative care aim to provide the right care at the right time for each individual patient, but palliative care should not substitute for appropriate hospice care services. The spectrum model of care for serious illnesses is demonstrated in Figure 1.

Figure 1. Old vs. New Model of End-of-Life Care



In addition to the similarities, many hospice providers also provide palliative care services. Furthermore, while a significant amount of palliative care is currently provided by hospitals as an "inpatient" service, there is an emerging shift to community/home-based palliative care, which will likely mirror the shift in recent decades to community/home-based hospice care.[12] And hospice providers often serve patients with a mix of general inpatient and residential care. Such care is likely the model for the provision of non-hospital-based palliative care.

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[10] Florida Department of Elder Affairs, "Hospice Demographic and Outcome Measures: 2017 Report." Florida Hospice Patient Discharges by Disposition, 2016: 17.4% of patient discharges were for "non-deaths."

[11] Ibid.

[12] Florida Department of Elder Affairs, "Hospice Demographic and Outcome Measures: 2017 Report. " The majority of patient care is provided in the place the patient calls "home." In addition to private residences, this may include nursing homes and residential facilities."

The Need for Palliative Care

According to the U.S. Centers for Disease Control and Prevention (CDC), 60% of U.S. adults live with at least one chronic disease and 40% of U.S. adults have two or more.[13]

Chronic diseases can cause patients a range of problems including loss of mobility and productivity, pain, depression, and difficulties with Activities of Daily Living (e.g., bathing, dressing, eating, and continence). The incurability, duration, and related complications make persons with chronic diseases some of the most frequent users of health care in the country, and the costs associated with chronic diseases, generally for acute treatment, are extraordinary.[14] Treatment for chronic and mental health conditions accounted for 90 percent of the nation's $3.3 trillion in annual healthcare expenditures in 2016.[15]

Chronic conditions also account for the vast majority of care (and spending) in publicly- funded healthcare programs. Nationally, more than two-thirds of Medicare (the single-payer federal health insurance program that provides health insurance for Americans aged 65 and older who have worked and paid into the system through the payroll tax) beneficiaries have two or more chronic conditions, and about one-in-seven have 6 or more.[16] More than 60 percent of Medicaid (the jointly funded federal and state program that assists with medical costs for eligible people with limited income and resources) enrollees have at least one chronic or disabling condition and 83 cents of every dollar spent in Medicaid [in 2011] goes to treating preventable and highly manageable chronic diseases including diabetes, asthma, and hypertension." [17]

Three chronic diseases – heart disease, cancer, and diabetes – "are the leading causes of death and disability in the United States [and] are also leading drivers of the nation's $3.3 trillion in annual health care costs."[18] The treatment of heart disease and stroke costs $190 billion annually[19] and treatment of diabetes costs $237 billion annually (based on 2017 direct medial spending).[20] Furthermore, a significant amount of such costs is for acute treatment – nearly one-third of the direct medical costs of diabetes treatment is hospitalization ("hospital inpatient care") and another 13% is physician office visits[21] – yet the disease itself is incurable and often the hospitalizations could have been avoided.

While acute care (e.g., physician visits and hospitalizations) of chronic conditions is a significant driver in total healthcare spending and a significant cost for the taxpayers who fund public healthcare programs,[22] acute care's curative approaches to treatment are often insufficient to treat the needs of patients with chronic conditions so such acute-curative

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[13] U.S. Centers for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP), "Chronic Diseases in America" (website), www.cdc.gov/chronicdisease/resources/infographic/chronic-diseases.htm (last accessed January 25, 2019).

[14] See, e.g., U.S. Center for Disease Control and Prevention, "Health and Economic Costs of Chronic Disease," (website) https://www.cdc.gov/chronicdisease/about/costs/index.htm#ref3 (last accessed January 25, 2019).

[15] The Center for Disease Control and Prevention, National Center for Chronic Disease Prevention and Health Promotion, Health and Economic Costs of Chronic Diseases, /www.cdc.gov/chronicdisease/about/costs/index.htm (last accessed November 5, 2018)

[16] "Multiple Chronic Conditions Among Medicare Beneficiaries: State-level Variations in Prevalence, Utilization, and Cost in 2011," Medicare & Medicaid Research Review, a publication of the U.S. Centers for Medicare & Medicaid Services Office of Information Products and Data Analytics. 2013.

[17] Partnership to Fight Chronic Disease, "Medicaid in a New Era: Proven Solutions to Enhance Quality and Reduce Costs," 2011.

[18] U.S. Centers for Disease Control and Prevention, "About Chronic Diseases" (website) www.cdc.gov/chronicdisease/about/index.htm (last accessed January 25, 2019).

[19] American Diabetes Association, Economic Costs of Diabetes in the U.S. in 2017," Diabetes Care May 2018; 41(5): 917-928 (available at https://doi.org/10.2337/dci18-0007)

[20] Benjamin EJ, Blaha MJ, Chiuve SE, et al. "Heart disease and stroke statistics—2017 update: a report from the American Heart Association." Circulation, Mar 7, 2017; 135(10): e146–e603 (available to download at www.ncbi.nlm.nih.gov/pmc/articles/PMC5408160/).

[21] American Diabetes Association, Economic Costs of Diabetes in the U.S. in 2017," Diabetes Care May 2018; 41(5): 917-928 (available at https://doi.org/10.2337/dci18-0007)

[22] See, e.g., Centers for Medicare & Medicaid Services, "Chronic Conditions among Medicare Beneficiaries, Chart Book," Baltimore, MD (2011) (available at /www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/Downloads/2011Chartbook.pdf) ("Medicare spending increased with the number of chronic conditions." page 23); Gerard Anderson, Ph.D., "Chronic Care: Making the Case for Ongoing Care," a report published by the Robert Wood Johnson Foundation (2010) (available at www.rwjf.org/content/dam/farm/reports/reports/2010/rwjf54583); Partnership to Fight Chronic Disease, "The Growing Crisis of Chronic Disease in the United States Fact Sheet," (undated), available at https://www.fightchronicdisease.org/sites/default/files/docs/GrowingCrisisofChronicDiseaseintheUSfactsheet_81009.pdf

interactions provide little improvement for the disease, despite the high costs of such acute care. This type of spending on "low value" treatment of advanced chronic illnesses (i.e., acute-curative care that is unlikely to be effective at curing the condition or disease) is a significant factor in driving up healthcare spending.

Palliative care creates an individualized treatment plan to focus proactively on coordinating a range of care services that address the diseases' symptoms and other complications (such as mobility issues) associated with the patient's condition (i.e., the chronic diseases or diseases), which are intended to improve the patient's quality of life but also – as this report shows – reduce the need for acute care interactions.

In addition to implications for quality of life, health care costs, and loss of productivity, the U.S. is also facing a growing number of individuals with chronic, advanced, and/or serious diseases as a result of increased life expectancy. In short, because modern medicine has succeeded in staving off many once-terminal conditions, there is a greater need than ever to more effectively address health concerns with which seriously or chronically ill patients may live for years or decades. For example, "in 2010, the costs of treating Alzheimer's disease were estimated to fall between $159 billion and $215 billion. By 2040, these costs are projected to jump to between $379 billion and $500 billion annually." [23]

National chronic condition figures are also reflected in Florida's healthcare patterns generally: more than one-half of adults in Florida live with at least one chronic condition, and, nearly one-third have two or more chronic conditions.[24] Furthermore, Florida has one of the largest elderly populations in the nation, and Florida's large elderly population exhibits higher incidences of chronic conditions. Florida has the second-highest number of hospice patients in the country (about 135,000 annually, behind only California),[25] and more than 18 percent of Florida's Medicare beneficiaries have six or more chronic conditions, the highest rate in the country (4 percentage points higher than the national average).[26]

In addition to quality of life for residents, the state may benefit economically from the expansion of palliative care. The CDC Chronic Disease Cost Calculator estimates the median 10-year-projected medical costs for a state for 10 different chronic conditions.[27] These costs range from $410 million for asthma to $1.8 billion for diabetes; absenteeism stemming from these conditions could cost states from about $5 million for individuals with congestive heart failure to $217 million for those with arthritis.[28]

In Florida, it is estimated that each chronic condition an individual has increases medical spending by an average of more than $2,000 a year.[29] Additionally, the onset of just one chronic condition is estimated to reduce individual earnings by 18 percent in the long term.[30]

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[23] U.S. Center for Disease Control and Prevention, "Health and Economic Costs of Chronic Disease," (website) https://www.cdc.gov/chronicdisease/about/costs/index.htm#ref3 (last accessed January 25, 2019).

[24] Partnership to Fight Chronic Disease, "The Costly Chronic Disease Epidemic in Florida," 2016.

[25] Florida Department of Elder Affairs, "Hospice Demographics and Outcome Measures 2018 Report," April 2018.

[26] Kimberly A. Lochner, Richard A. Goodman, Samuel Posner, Anand Parekh, "Multiple Chronic Conditions Among Medicare Beneficiaries: State-level Variations in Prevalence, Utilization, and Cost, 2011," Medicare & Medicaid Research Review, Vol.3, No. 3, 2013.

[27] 10-year medical cost projections for arthritis, asthma, cancer, congestive heart failure, coronary heart disease, hypertension, stroke, other heart diseases, depression, and diabetes.

[28] Centers for Disease Control and Prevention, "Costs of Chronic Diseases at the State Level: The Chronic Disease Cost Calculator, "Preventing Chronic Disease Journal. September 2010.

[29] Partnership to Fight Chronic Disease, "The Costly Chronic Disease Epidemic in Florida," 2016.

[30] Ibid.

The Benefits of Palliative Care

Multiple studies have shown the benefits of palliative care and there is "a growing body of evidence supporting its ability to achieve the Triple Aim: improving the patient experience of care, improving health, and reducing unnecessary medical interventions and their associated costs."[31]

Palliative care can reduce healthcare costs by minimizing ineffective services, reducing hospitalizations (or readmissions), and shortening lengths-of-stay. "A systematic review of forty-six high-quality studies, predominately from the United States, demonstrated consistent and significant reductions in hospitalization and total spending in association with palliative care services."[32] It has also been shown to reduce the intensity of required care by ameliorating pain, distress, and other symptoms that cause medical complications, increase care intensity, and prolong hospital lengths-of-stay.[33] These types of benefits could help reduce overall costs, or 'bend the healthcare cost curve' for the patients and the state.

In one study, the total cost of health services used within six months by discharged patients who received hospital-based palliative care averaged $14,486 while a comparable group that did not receive palliative care averaged $21,252 in total health costs in the same period. [34] Thus, palliative care contributed to a cost mitigation of 32 percent. Over a shorter period, another study found an average reduction of $4,098 in healthcare spending for palliative care patients.[35]

Driving these savings was a significant difference in hospital readmission costs for palliative care recipients versus others. Even among patients who died in the hospital, those receiving palliative care incurred 10 percent fewer healthcare costs ($61,241, compared to $68,804) than those who did not.[36]

Palliative care has also been shown to reduce the intensity of required care. An average savings of $2,678 in intensive care unit spending per hospital admission for individuals who received palliative care demonstrates that palliative care is successful in ameliorating pain, distress, and other symptoms that cause medical complications, increase care intensity and prolong hospital lengths-of-stay.[37]

Palliative care interventions have been found to directly reduce depression in patients by as much as 75.6 percent and reduce average difficulties with Activities of Daily Living by 33.7 percent.[38] Both interventions reduced per capita societal healthcare costs, increased quality-adjusted life-years,[39] and reduced mortality. By this estimate, palliative care could reduce societal health care costs by an estimated $103 billion in the next two decades.[40] Furthermore, palliative care has been shown to mitigate hospital costs by reducing the frequency of 9-1-1 calls, emergency department visits, and unnecessary urgent hospitalizations.[41]

Coordination of care and improved communication between professionals, patients, and patients' families through palliative care have also been shown to

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[31] Diane Meier, Anthony Back, Amy Berman, Susan Block, Janet Corrigan, and R. Sean Morrison, "A National Strategy for Palliative Care," Health Affairs, 36:7; 1265-1273, 1266 (July 2017).

[32] Diane Meier, Anthony Back, Amy Berman, Susan Block, Janet Corrigan, and R. Sean Morrison, "A National Strategy for Palliative Care," Health Affairs, 36:7; 1265-1273, 1266 (July 2017).

[33] Morrison, R.S., Penrod, J.D., Cassel,J.B., et al, "Cost Savings Associated with U.S. Hospital Palliative Care Consultation Programs." Archives of Internal Medicine, September 2008.

[34] Smith, S., Brick, A., Normand, C., "Evidence on the Cost and Cost-Effectiveness of Palliative Care: A Literature Review," Palliative Medicine, July 2013.

[35] R. Sean Morrison, Jessica Dietrich, Susan Ladwig, et.al., "Palliative Care Consultation Teams Cut Hospital Costs for Medicaid Beneficiaries," Health Affairs Vol. 30, No. 3, March 2011.

[36] Ibid.

[37] Aslakson, R., Cheng, J., et.al., "Evidence-Based Palliative Care in the Intensive Care Unit: A Systematic Review of Interventions. Journal of Palliative Medicine," February 2014.

[38] Adam Singer, Duncan Leaf, Manali Patel, et.al., "Projecting the Impact of Implementing Palliative Care for Older Adults: What Does the Evidence Support?," Journal of Pain and Symptom Management. February 2017.

[39] Quality-adjusted life-year (QALY) is a generic measure of disease burden, including both the quality and the quantity of life lived. It is used in economic evaluation to assess the value for money of medical interventions. One QALY equates to one year in perfect health.

[40] Supra, see footnote 21.

[41] Harriet L. Kosimar and Judy Feder, "Transforming Care for Medicare Beneficiaries with Chronic Conditions and Long-Term Care Needs: Coordinating Care Across All Services, The Scan Foundation, October 2011.

improve satisfaction of care ratings.[42] Early and concurrent palliative care has been found to improve multiple patient outcomes, including quality of life, mood, and survival.[43] More generally, a 2017 report concludes that broad improvements in chronically ill patients are well within reach.[44] Outpatient palliative care has been shown by a number of studies to reduce hospitalizations and emergency room visits, among other benefits.[45]

Altogether, these and dozens of other studies constitute substantive evidence that palliative care aids in both patient quality of life and care cost reductions, a unique value proposition, and one that is positioned to address growing needs among patient populations.

The success of palliative care as a means to improve patient outcomes and reduce costs has prompted growth of inpatient palliative care programs in hospital settings. In 2015, 67 percent of U.S. hospitals with 50 or more beds reported one or more palliative care teams, up from 63 percent in 2011.[46] However, the availability of inpatient palliative care in hospital settings is likely tied to the hospital's overall capacity and typically tracks hospital size. For example, nationwide, 90 percent of hospitals with 300 beds or more were found to have a palliative care program, compared to only 56 percent of hospitals with fewer than 300 beds.[47]

Community/home-based palliative care (CBPC) – "Community/home-based services were defined as an organized service that provides palliative care to patients in their private residences, assisted living facilities, nursing homes, or wherever patients reside"[48] – could greatly expand access to palliative care in some areas in addition to reducing costs and improving patient outcomes system-wide. Home-based palliative care has been found to increase patient satisfaction and reduce the use and costs of medical services and facilitate more appropriate and timely utilization of hospice services when the patient's illness reaches its end stage.[49]

Expansion of community/home-based palliative care may efficiently meet the needs of the growing number of patients that would benefit from palliative care services, improve patient quality of life, and net significant health savings in the long run. This is consistent with trends in hospice care moving toward community/home-based care. Still, community/home-based palliative care has been slower to gain traction than inpatient palliative care services.

Expanding these care models may present Florida with unique opportunities to improve health care choices for seriously and chronically ill patients while supporting

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[42] Jeffifer S. Temel, Joseph A. Greer, Alona Muzikakski, et.al., "Early Palliative Care for Patients With Metastic Non-Small-Cell Lung Cancer," New England Journal of Medicine, August. 2010.

[43] Temel, Jennifer S., et. al., "Early Palliative Care for Patients with Metastatic Non–Small-Cell Lung Cancer," New England Journal of Medicine, August 2010; 363:733-42

[44] Clarke, J.L., Bourn, S., Beck, E.H., and Castillo, D.J., "An Innovative Approach to Health Care Delivery for Patients with Chronic Conditions," Population Health Management, 2017.

[45] See, e.g., Leslie J. Blackhall, Paul Read, George Stukenborg, et.al., "CARE Track for Advanced Cancer: Impact and Timing of an Outpatient Palliative Care Clinic," Journal of Palliative Medicine, Vol 19; Issue 1, Jan 2016 "Several recent studies suggest that integration of outpatient palliative care services into the care of patients with advanced cancer can improve care by decreasing troubling symptoms [Footnotes 1–6] and reducing the rate of hospitalization, emergency department visits, and chemotherapy at the end of life. [Footnotes 7–10]"

[46] America's Care of Serious Illness 2015 State-By-State Report Card on Access to Palliative Care in Our Nation's Hospitals, Center to Advance Palliative Care, National Palliative Care Research Center. 2015.

[47] Dumanovsky, Tamara, et. al, "The growth of palliative care in US hospitals: a status report." Journal of Palliative Medicine, Vol 19; Issue 1, Jan 2016. In addition to hospital size, other institutional characteristics are strongly associated with the presence of a hospital palliative care program. Only 45 percent of Sole Community Provider hospitals (those located more than 35 miles from other like hospitals) were found to have palliative care programs, compared to 69 percent of non–Sole Community Providers. Other variables associated with hospital palliative care programs include the presence of an American College of Graduate Medical Education accredited residency training program, hospital members of the Association of American Medical Colleges, hospitals operated by the Catholic Church, and institutions that owned or had a financial relationship with a hospice program.

[48] Palliative Care in Florida: A Report to the Surgeon General of the Florida Department of Health by the Palliative Care Ad Hoc Committee. June, 2016. Available at: https://issuu.com/floridahealth/docs/palliative_care_in_florida__2016.

[49] Brumley, Richard, "Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of In-Home Palliative Care," Journal of American Geriatric Society. June 2007.

financially savvy health care planning. Furthermore, current hospice providers have the expertise, skill, and capacity to provide these palliative care services upstream to patients in various community settings, and many are already doing so.

Palliative Care in Florida

In 2014, the World Health Organization called for access to palliative care as a human right, yet much work needs to be done to ensure that most Floridians have such access. Furthermore, the demand in Florida is clear and the opportunity to generate significant cost savings, especially important for taxpayer-funded healthcare programs, is great.

Recognizing the potential cost-savings associated with palliative care services, Florida's Surgeon General created a *Palliative Care Ad Hoc Committee* (PCAHC) in 2015 to serve as an advisory body to the Florida Department of Health.[50] To evaluate current palliative care initiatives across the state, the PCAHC surveyed providers of palliative care.

The PCAHC reported that 91 percent (n=39) of non-hospice palliative care programs were available only in hospital or inpatient settings, 33 percent made home- or community-based services available, and 16 percent provided services across more than one setting.[51] The report also provided evidence of the demand in Florida finding that 77 percent of palliative care programs reported increases in capacity (e.g., funding, staff, patients served, etc.) in 2015. However, the PCAHC found that fewer than 50 percent of Florida counties offered sufficient levels of palliative care based on "estimated need" calculated by the PCAHC.[52] Furthermore, a 2015 national ranking of prevalence and distribution of palliative care programs in hospitals gives Florida a "C" grade.[53] This has improved as hospitals have stepped forward to fill the need.

There are challenges that explain why palliative care is not as widely accessible as would be ideal, which will be explored in the next section, and there are opportunities for fostering the expanded access to, and use of, palliative care services in Florida.

It is likely that hospice providers will play a vital role in expanding palliative care in Florida. While there is no definitive measure of the coverage of Florida's population by hospice providers that also offer palliative services, it is likely that the hospice providers that offer palliative (or pre-hospice) services cover much if not most of the state's population.[54]

Challenges

Despite the benefits of palliative care and the opportunity for expansion of community-based services, some challenges remain that must be properly addressed, including: financial stability and lack of service reimbursement systems, lack of public awareness, workforce shortages, professional education/training deficiencies, and regulatory barriers.

The most significant challenge to expanding palliative care is financial sustainability. Historically, most palliative care providers (including hospice agencies) have sought government payment sources to fund their services. Medicare Part B reimburses physicians, nurse practitioners, psychologists, and, in limited situations, licensed clinical social worker services and home health reimbursement. Outside of hospice and hospital settings, these sources rarely cover the full cost of palliative care. Providers may also pursue less

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[50] Palliative Care Ad Hoc Committee, "Palliative Care in Florida: A Report to the Surgeon General of the Florida Department of Health," June, 2016, retrieved from https://issuu.com/floridahealth/docs/palliative_care_in_florida__2016, June 6, 2018.

[51] Ibid.

[52] Melissa Baniak, Philip Cavicchia, Melissa Jordan, "Assessing Palliative Care Capacity and Need in Florida," Florida Department of Health, June 2017. Retrieved from https://cste.confex.com/cste/2017/webprogram/Paper7957.html, June 4, 2018.

[53] Center to Advance Palliative Care, "America's Care of Serious Illness: 2015 State-By-State Report Card on access to palliative care in our nation's Hospitals," Table 1 (page 24): "Prevalence and Distribution of Palliative Care Programs in U.S. Hospitals by State and U.S. Census Region."

[54] Discussions with major nonprofit hospice providers and experts with the Florida Hospice and Palliative Care Association.

traditional payment sources like grants, commercial insurance contracts, Accountable Care Organizations, and private pay/concierge models, but overall, the lack of sustainable funding for the provision of palliative care remains a barrier to expansion.[55]

Lack of public awareness is also a significant barrier to expanding palliative care. There is a demonstrable need to provide more and better information about the role of palliative care services. Additional information about the merit and value of palliative care (regarding patient outcomes and cost) may also help foster support for and participation within these programs. Similarly, prioritizing the introduction of palliative care service to patients and their families and proffering palliative care as a concurrent part of treatment protocols is an important part of developing comprehensive care plans. This early introduction supports patient-provider relationship building, future decision-making, and pain management strategies, features of palliative care provision that are instrumental to its success.

Another issue is workforce availability and development. While some palliative care programs are able to provide quality service without a full team, ideal comprehensive care includes physicians, nurses, social workers, and more niche positions including child life specialists, psychologists, and chaplains. Encouraging adequate palliative care education and training opportunities within the healthcare sector is vital for ensuring access to comprehensive palliative care. There are relatively few palliative care medicine fellowships available throughout the U.S., resulting in a widening gap between the supply of Board-certified Hospice and Palliative Medicine physicians and the demand.

A challenge to providing community-based palliative care efficiently is ensuring that the care is provided to the right patients. Targeting palliative care to the appropriate population is critical to its value.[56] Identification of such patients requires the right data in combination with an effective algorithm and/or vigilant administrative staff (ideally both). Screening tools that are both sensitive (i.e., identify as many of those at risk as possible) and specific (i.e., exclude individuals who do not need services or are unlikely to benefit from them) are an instrumental part of identifying these patients, especially since many may be unaware of or have limited familiarity with non-hospice outpatient palliative care. Patient engagement is an on-going challenge for most community-based programs.

Similarly, ensuring the right level of palliative care is vital. Community-based palliative care ranges significantly in the amount of services provided based on a patient's individual needs. Ensuring the right amount and type of services is important to efficiency and patient outcomes.

In 2015, 35 percent of all palliative care programs in the state were hospice-owned; 58 percent relied on ongoing hospital support; 72 percent were primarily funded by billing; and 33 percent relied on philanthropy and/or foundation grant(s).[57] Each of these sources imposes various restrictions, usually limited duration, limited target populations, and/or limited funds. These reimbursement agreements typically hinge on palliative care more than offsetting costs that would otherwise be incurred (especially long stays in hospitals and Intensive Care Unit level support). While the system-wide cost savings and improved outcomes are helping generate interest in and growth of palliative care programs, financial support is usually insufficient for this kind of care to be widely provided as a stand-alone service eligible for more uniform reimbursement outside of hospice and hospital settings.

Policymakers are in a unique position to support coordinated action to address these barriers in a way that is most effective. "The lack of policy supports for

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[55] Walter Borginis, Carla Braveman, Sharyl Kooyer, et.al., "NAHC HHFMA Palliative Care White Paper," National Association of Home Care & Hospice and Home Care and Hospice Financial Managers Association. June 2015.

[56] Jeffrey Cohn, Janet Corrigan, Joanne Lynn, et.al., "Community-Based Models of Care Delivery for People with Serious Illness," National Academy of Medicine, April 13, 2017.

[57] Palliative Care in Florida: A Report to the Surgeon General of the Florida Department of Health by the Palliative Care Ad Hoc Committee. June 2016. Accessed via https://issuu.com/floridahealth/docs/palliative_care_in_florida__2016.

palliative care contributes to preventable suffering and low-value care." [58] For instance, public awareness efforts around palliative care need to coincide with programs to support and enhance clinicians' knowledge and skills to provide those services, as well as endorsed mechanisms to pay for them.[59] Allowing the delivery of palliative care in settings such as hospice inpatient facilities may also be helpful.

Conclusion and Recommendations

Patient-centered palliative care has been shown to improve patient outcomes and quality of life while reducing overall healthcare costs by minimizing utilization of ineffective services, shortening length of stay, and lowering the likelihood of hospital readmission. Despite this success, palliative care is available at sufficient levels in fewer than one-half of Florida counties. Increasing access to palliative care can play an important role in improving patients' quality of life and reducing healthcare spending.

There is a role for policymakers to increase access to palliative care, especially home and community based palliative care. Allowing the delivery of palliative care in settings such as hospice inpatient facilities may also be helpful.

> *"Policy can broaden the focus of palliative care for the seriously ill beyond health systems and into homes and communities. Where patients prefer to be and where care has been demonstrated to be of high quality and lower cost."* [60]

> *"Given the states' role in funding safety-net programs, as well as the fact that historical precedent and early signs indicate a push towards both more privatization of Medicare and Medicaid and greater state control in health care delivery and payment, states should consider levers to expand local access to palliative care…As the need for greater access to palliative care is better understood, more states are creating policies intended to support its quality and expansion."* [61]

While Florida TaxWatch generally supports the recommendations to advance the provision of palliative care services contained in the *Palliative Care Ad Hoc Advisory Committee's* June 2016 report, the state should implement the following recommendations.

For the state to realize the cost-savings benefits of palliative care, the payment/reimbursement system must be addressed. To ensure the financial stability of palliative care providers, a system of care reimbursement that can be used by public and private payors must be developed. But a definition of the services that constitute palliative care is a prerequisite for such a payment system. Therefore, the Legislature must develop a regulatory framework for palliative care.

The regulations must balance the competing interests of protecting patients from being harmed by providers that do not have the expertise or capacity to provide appropriate and comprehensive palliative care services while avoiding overly burdensome regulations that will stifle growth and expansion. The deliberations to develop this framework should include stakeholders, providers, and experts. The regulations must protect the quality of care while still ensuring the flexibility of models of care to allow for unique, patient-centered care, recognizing that "one size does not fit all."

First, either the Legislature or an appropriate agency at its direction, should develop a definition of palliative care and set minimum standards of available services that providers must meet to be able to claim they provide palliative care. These standards should be consistent with national standards of service for palliative care.

Additionally, the Legislature or an appropriate agency at its direction, must develop regulatory requirements and oversight mechanisms (whether through

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[58] Diane Meier, Anthony Back, Amy Berman, Susan Block, Janet Corrigan, and R. Sean Morrison, "A National Strategy for Palliative Care," Health Affairs, 36:7; 1265-1273, 1266 (July 2017).

[59] Stacie Sinclair, Diane E. Meier, "How States Can Expand Access to Palliative Care," Health Affairs. January 2017.

[60] Diane Meier, Anthony Back, Amy Berman, Susan Block, Janet Corrigan, and R. Sean Morrison, "A National Strategy for Palliative Care," Health Affairs, 36:7; 1265-1273, 1266 (July 2017).

[61] Stacie Sinclair, Diane E. Meier, "How States Can Expand Access to Palliative Care," Health Affairs. January 2017.

accreditation, licensing, or otherwise) to ensure that the standards are met, again in consultation with stakeholders and providers, and being conscious of the concern of stifling the growth and expansion if the oversight is too burdensome.

The regulatory framework should also identify and remove any legal barriers that limit hospice providers from providing upstream palliative care to appropriate patients.

Additionally, the Legislature should invest in programs that increase training opportunities to address workforce shortages. Like with many areas in healthcare and long-term care, workforce shortages are a major barrier to expansion of palliative care. To address this issue, the Legislature should fund increased palliative medicine fellowships, provide incentives for palliative care fellows to remain in Florida, invest in expanding training programs for nurses, and fund internship opportunities. Each of these were recommendations of the *Palliative Care Ad Hoc Advisory Committee.*

The Legislature can also play a role in increasing public awareness. While creating the framework and increasing training opportunities will inherently raise public awareness, the appropriate agencies should be directed to pursue activities that increase awareness in the medical community and the public generally, such as those recommended by the *Palliative Care Ad Hoc Advisory Committee.*

Finally, Florida TaxWatch recommends that Florida policymakers explore implementing pilot programs to realize the potential benefits of community-based palliative care programs in Florida. Expanding community-based palliative care may present Florida with unique opportunities to improve health care choice for seriously and chronically ill patients while supporting financially sensible health care planning. Furthermore, current hospice providers likely have the expertise, skill, and capacity to provide these palliative care services upstream to patients in various community settings.

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