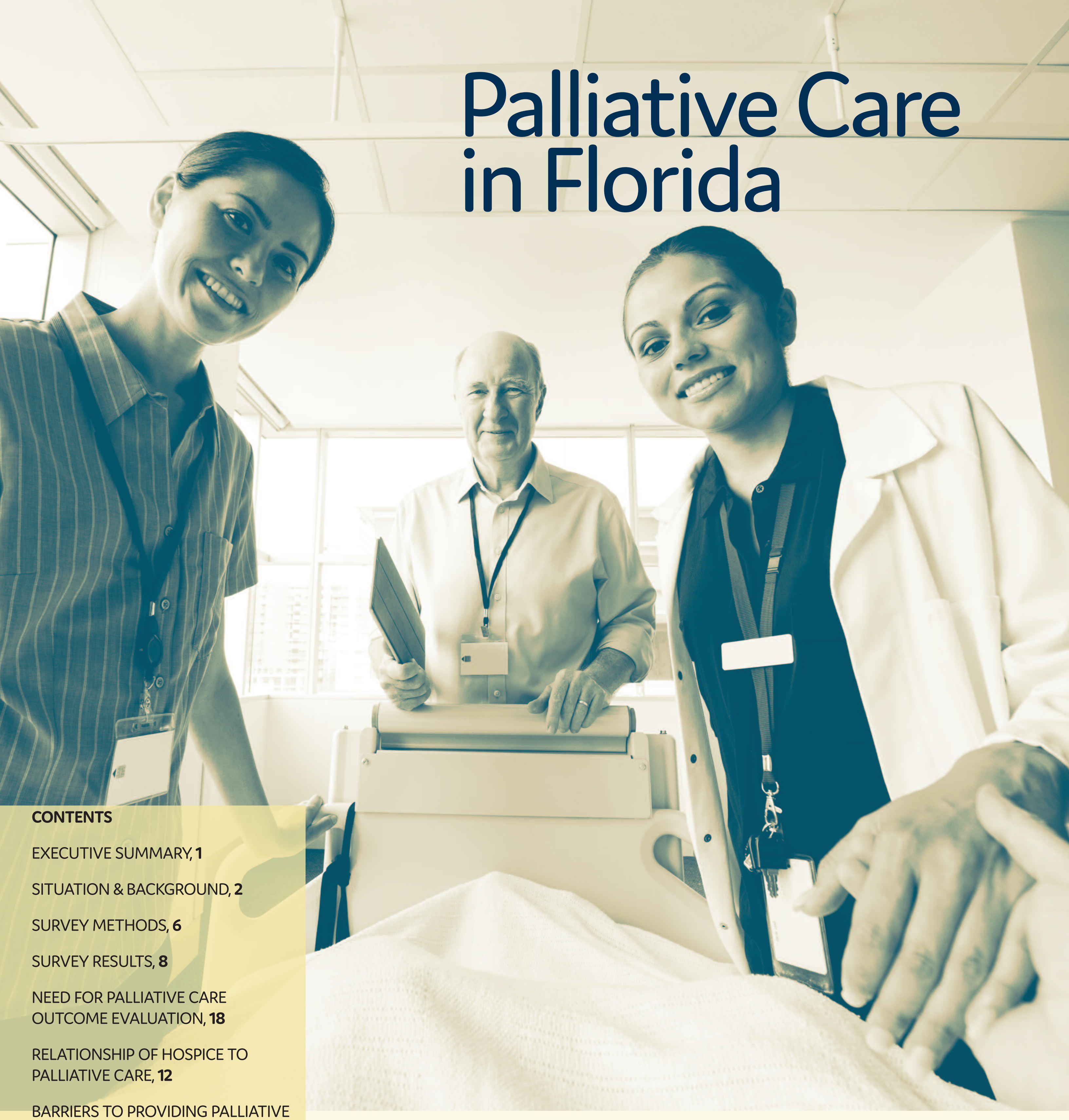
Palliative Care in Florida



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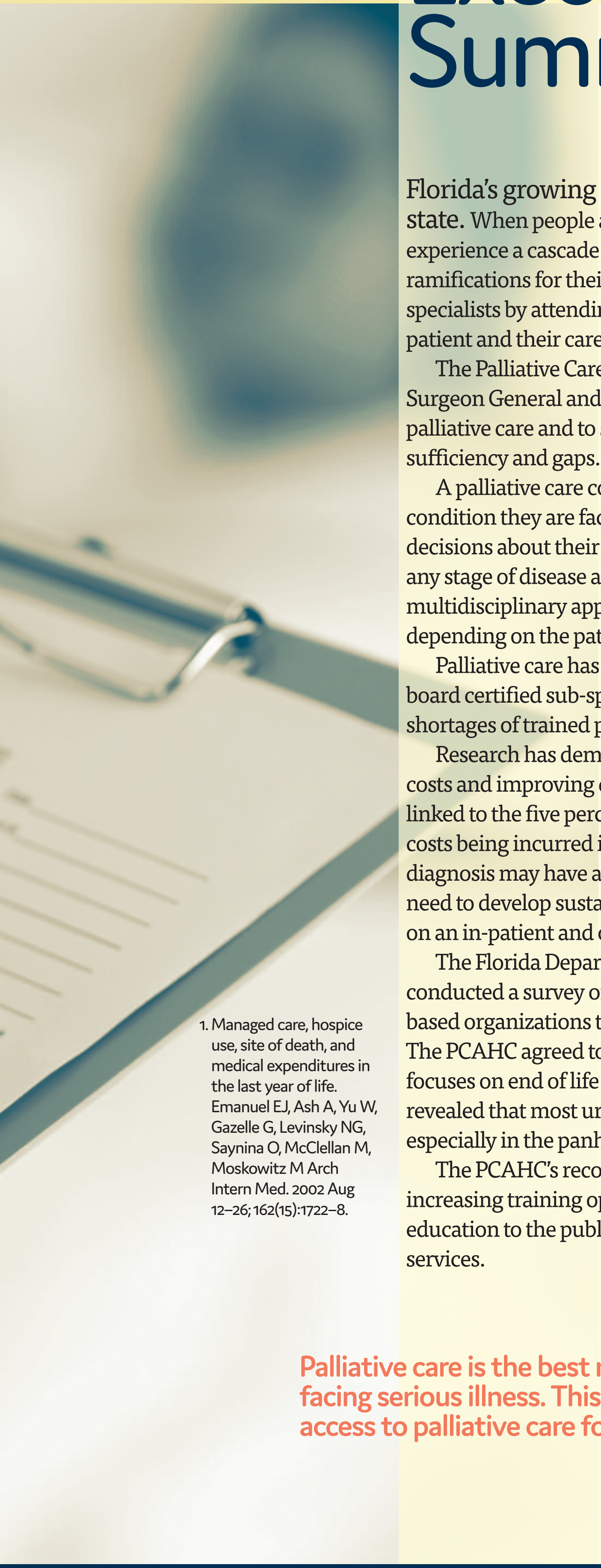
A Report to the Surgeon General of the Florida Department of Health

Palliative Care Ad Hoc Committee
June 30, 2016

Florida HEALTH

Executive Summary



Florida's growing citizenry benefits from high quality health care in our state. When people are diagnosed with a serious or chronic condition, they experience a cascade of feelings and concerns about their prognosis and its ramifications for their loved ones. Palliative care services assist the treatment specialists by attending to the physical, psychological, and spiritual needs of the patient and their caregivers.

The Palliative Care Ad Hoc Committee (PCAHC) was appointed by Florida's Surgeon General and Secretary of Health to provide a comprehensive definition of palliative care and to survey Florida's health care providers to identify service delivery sufficiency and gaps. This report is the result of their work.

A palliative care conversation informs the patient and loved ones about the condition they are facing and their prognosis so that they are better equipped to make decisions about their own goals of care. Palliative care is appropriate at any age and at any stage of disease and is provided concurrent with curative treatment. It is a multidisciplinary approach and utilizes a team of specialists to alleviate suffering depending on the patient's needs.

Palliative care has been practiced for many years, but palliative medicine became a board certified sub-specialty in 2006. The demand for services continues to grow, and shortages of trained professionals exist throughout the state.

Research has demonstrated that palliative care is cost-effective, reducing medical costs and improving quality of life.[1] Since 30 percent of Medicare expenditures are linked to the five percent of beneficiaries dying each year, and with one-third of those costs being incurred in the last month of life, palliative care conversations that start at diagnosis may have a big impact on those costs. As the demand grows, so will the need to develop sustainable funding mechanisms for palliative care providers, both on an in-patient and out-patient basis.

The Florida Department of Health, working with the experts on the PCAHC, conducted a survey of Florida palliative care providers in hospitals and community-based organizations to assess the need, capacity, and sufficiency of available services. The PCAHC agreed to exclude hospice providers from the survey, since hospice focuses on end of life care, and palliative care should start at diagnosis. The survey revealed that most urban areas of the state have some capacity while rural areas, especially in the panhandle, have little access to palliative care services.

The PCAHC's recommendations focus on strengthening minimum standards, increasing training opportunities for health care practitioners, and providing education to the public and the health care sector about the value of palliative care services.

Palliative care is the best mechanism to improve the quality of life for Floridians facing serious illness. This report identifies the next steps to pursue in expanding access to palliative care for all Floridians who need it.

1. Managed care, hospice use, site of death, and medical expenditures in the last year of life. Emanuel EJ, Ash A, Yu W, Gazelle G, Levinsky NG, Saynina O, McClellan M, Moskowitz M Arch Intern Med. 2002 Aug 12–26; 162(15):1722–8.

Situation & Background

Situation: Expanding palliative care services is the solution to Florida's growing need for chronic disease and cancer treatment provision.

Working Definition and Essential Elements of Palliative Care

Palliative care is a multidisciplinary approach to specialized medical care for people with a serious illness. It focuses on providing relief from the symptoms, pain, and stress of a serious illness. Palliative care is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

The goal is to improve quality of life for the patient, family, and caregiver. Palliative care utilizes a multidisciplinary approach to patient care, relying on input from physicians, pharmacists, nurses, chaplains, social workers, psychologists, and other health professionals in formulating a plan of care to relieve suffering in all areas of a patient's life.[2]

Advances in health care delivery and access to treatment have resulted in longer lives for Floridians who are managing chronic disease. Managing chronic disease successfully requires an on-going relationship with a health care team, and control of all related symptoms (i.e., physical, psychological, and spiritual). When chronic disease is not adequately managed, repeat hospital admissions can result, creating additional costs, health risks, and stress on both the patient and the patient's family.

As of 2006, palliative medicine became a board certified sub-specialty of internal medicine and the rising demand for clinical palliative care resources has led to rapid growth in the number of patients receiving palliative care in the United States. Despite this growth, large gaps still exist between patients needing palliative services and the number of trained providers.

Research has demonstrated the value of beginning to provide palliative care services at the time of diagnosis. One significant study was conducted in 2010 at Massachusetts General Hospital, dividing 151 advanced lung cancer patients into a randomized clinical trial with one group receiving oncologic and palliative care starting at diagnosis and the other receiving oncologic care alone.[3] The study group met with a palliative care team that included nurses and social workers, who addressed the psychological and support needs of the patient and their family and caregivers. They reported less depression and had fewer medical or surgical interventions as the disease progressed compared to the control group. Despite less "aggressive" treatment, the palliative care group had longer survival times coupled with a higher quality of life than the control group (11.6 months versus 8.9 months). In 2013, the team at Massachusetts General published another study of a retrospective review of the medical records of all the patients in the 2010 randomized trial.

This review identified key elements of care delivered by the palliative care team:

- **Building relationship and rapport, including engaging family members**
- **Addressing symptoms and coping**
- **Establishing health education for a more thorough understanding of illness**
- **Discussing cancer treatments**
- **Planning for end of life and assisting with other decision-making**

Providing those elements of care were essential to improving quality of life and extending life span following diagnosis.[4]

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2. Center for the Advancement of Palliative Care. www.capc.org
3. Temel, Jennifer S. et al. "Early Palliative Care for Patients with Metastatic Non-Small-Cell Lung Cancer." The New England Journal of Medicine 363, no. 8 (August 19, 2010): 733–742
4. Yoong, Jaclyn et al. "Early Palliative Care in Advanced Lung Cancer: a Qualitative Study."

The Committee met on November 17, 2015 and agreed upon a comprehensive definition of palliative care, which includes the following key components:

- More than pain management
- Not only associated with end of life care; different than hospice care
- Ideally incorporated at earlier stages of illness
- Involves care coordination
- Appropriate for all ages
- Includes alleviating symptoms and broadening services to improve quality of life
- Includes mental, emotional, psychological, and spiritual support
- Incorporates long-term survivorship issues; recognizes that cancer can leave long-term treatment effects, which often require on-going symptom management to optimize quality of life
- Includes provision of factual information to support autonomous decision-making for medical decisions, treatment goals, and other care
- Helps to maintain health as long as possible in the absence of a cure
- Recognizes the needs of family and caregivers, including respite care, counseling, and coping skills

In short, establishing a palliative care protocol for the patient at time of diagnosis helps the patient live longer and reduces costs and unnecessary suffering for both the patient and the family with clear goals of care aligned with plan of care.

Palliative care reduces hospitalizations and readmissions resulting in better quality of care and better utilization of resources, which is better for patients and saves money. About 18% of hospitalized Medicare patients are readmitted within 30 days.[5] The Florida Hospital Association established the Collaborative on Reducing Readmissions in Florida in 2008 with the goal of using Agency for Health Care Administration (AHCA) data to understand the problem and develop hospital best practices to reduce readmissions. Florida was the first state in the country to publish readmission rates on a consumer website. The data showed:

- **7% of patients had potentially preventive readmissions**
- **83% of those visited the Emergency Room and were then readmitted**
- **Average length of stay was 6.1 days**
- **26% of patients were readmitted to a different hospital**[6]

Palliative care reduces overall hospital spending considerably. An important study found a palliative care consultation led to reductions in direct hospital costs of $1,700 per patient who lived and almost $5,000 for patients who died. By providing palliative care beginning at diagnosis, and with simultaneous treatment, hospitalizations are reduced. If a hospital has 400 beds, and has an interdisciplinary palliative care team who works with 500 patients, the hospital could save $1.3 million per year.[7]

BACKGROUND OF THE PALLIATIVE CARE AD HOC COMMITTEE

Recognizing the importance of these services, former Florida State Surgeon General and Secretary of Health, Dr. John H. Armstrong, appointed a group of experts to the Palliative Care Ad Hoc Committee in November 2015. The purpose of this committee was to provide advice and analysis to the Florida Department of Health (Department) regarding palliative care opportunities available in Florida with a focus on palliative care services available to cancer patients.

The goals and objectives of the Committee were as follows:

- **Define a comprehensive definition of palliative care**
- **Conduct a survey/environmental scan of existing palliative care services in Florida**
- **Perform an outcome evaluation on current palliative care initiatives**
- **Create a report that includes recommendations on provider and public education about palliative care**

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5. Orlando Business Journal, www.Bizjournals.com, The 10 Florida hospitals being fined the most for readmissions, 10-7-2014, accessed 5-30-16

6. www.collab.fha.org, Collaborative on Reducing Readmissions in Florida. 2008. Accessed 5-20-16.

7. Morrison RS, Penrod JD, Cassel JB, et al. Cost savings associated with US hospital palliative care consultation programs. Arch Intern Med. 2008 Sep 8;168(16):1783–90.

personal stories

Lee Memorial Hospital's Palliative Care Program

Mary was diagnosed with breast cancer 5 years ago. She tries to keep her life as normal as possible while she and her husband raise their three small children. She has constant pain in her back and chest from where her cancer has spread, and burning pain in her hands and feet from the side effects of her chemotherapy. She feels overwhelmed coordinating her care and trying to spend quality time with her family.

Lee Memorial's palliative care providers joined Mary's health care team to help control her pain, assist in coordination of care and provide emotional support. The palliative care team monitors her progress electronically in hopes to anticipate when she may need support. She recently was hospitalized for a lung blood clot. Palliative care was there every day during her hospital stay. When she was discharged on the weekend and had difficulty getting her prescriptions filled, the palliative care team contacted the pharmacy and had the medications filled and waiting for her when she arrived at the pharmacy.

Today, Mary's cancer is not cured but her pain is controlled. One of Mary's biggest worries was not knowing what to expect in the future. She has had many opportunities to talk with her palliative care team about her illness, her hopes and fears for her family, and what she wants in the future. She feels a weight has been lifted off her shoulders since she has been able to speak openly about her cancer journey.

One of Mary's biggest worries was not knowing what to expect in the future.

Arnold Palmer Medical Center—Orlando Health

Harper was a 4 month old female with a new diagnosis of a malignant brain tumor. The Pediatric Palliative Care team was consulted the day after admission for family support and care coordination. The family initially had concerns about burdens/benefits of treatment with its implications on quality of life. The Pediatric Palliative Care team explored goals of care and aligned the treatment plan accordingly. Harper received intense chemotherapy for her brain tumor understanding that the chance of a cure was minimal. The Pediatric Palliative Care team treated her irritability and pain through pharmacologic and non-pharmacologic measures. After her second cycle of chemotherapy, she had chemotherapy-related toxicities leading to escalation of support including the need to place her on a breathing machine. Given chemotherapy's toxicities, Harper would not be able to pursue any further intense curative chemotherapy which allowed her family to re-frame goals. The Pediatric Palliative Care team had several interdisciplinary family meetings to discuss short-term goals, future decisions, and the quality of days (as opposed to quality of life). Her family decided to discontinue the ventilator and support her through additional comfort measures. Two days after removal of ventilator, the family was able to capture some amazing memories for legacy building. The family enjoyed time with Harper not as a cancer patient but as their daughter. Later that day, the family asked to go home with hospice. The mother had made a promise early on to take Harper home. Through much coordination between the Pediatric Palliative Care team and a community hospice, within just a few hours, her parents were able to fulfill that promise and she died in her mother's arms shortly after getting home.

> The family enjoyed time with Harper not as a cancer patient but as their daughter.

Although the Palliative Care Ad Hoc Committee was charged with looking at cancer burden, palliative care services apply to all causes of serious illness. The Committee stressed the difference between palliative and hospice care throughout its work. However, the list of leading causes of death from those using hospice is instructive in reminding us that palliative care has merit across many diseases.

HOSPICE UTILIZATION TRENDS 2015[8]

1. **Alzheimer's disease**
2. **Congestive Heart Failure, unspecified**
3. **Lung Cancer**
4. **Chronic Obstructive Pulmonary Disease**
5. **Senile Degeneration of the Brain**
6. **Parkinson's disease**
7. **Heart disease, unspecified**
8. **CVA/Stroke**
9. **Cerebral Atherosclerosis**
10. **Breast Cancer**

The second goal of the Committee was to advance the state's use and understanding of palliative care by conducting a statewide needs assessment of current palliative care services in Florida. To achieve this, the Department conducted an environmental scan by surveying hospitals and hospice/palliative care programs in Florida.

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[8] https://www.gpo.gov/fdsys/pkg/FR-2016-04-28/pdf/2016-09631.pdf

Survey Methods

In 2015, the California HealthCare Foundation conducted a study to understand the supply of palliative care in California relative to the estimated need for such services. The approach described below was modelled after these methods. A summary of California's approach can be found in Appendix B.

PALLIATIVE CARE PROGRAM IDENTIFICATION

The Department reviewed information from the American Hospital Association (AHA), Center to Advance Palliative Care (CAPC), Florida Health Finder, and county-specific Google searches to identify hospitals and hospice/palliative care programs in Florida. The Department used data from the 2014 AHA annual survey to exclude 67 hospitals that indicated they did not have a palliative care program.

To procure participation, Department staff contacted each hospital and hospice/palliative care program by phone. For hospital contacts, it was first determined if they had a palliative care program. An explanation of the project was provided and willingness to participate was determined. Participants were emailed an ID Number and a link to the survey.

PALLIATIVE CARE DEFINITION

For the purposes of the survey, the Department defined palliative care as 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. 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.

CAPACITY

Based on the number of patients served (inpatient and outpatient), as reported by each respondent, capacity was calculated for each county. Capacity was defined as the number of patients served in 2015. Inpatient and Outpatient services were calculated separately for each county.

inpatient capacity

Table 1a: AHCA Data					
RESPONDENT ID	HOSPITAL	TOTAL PATIENTS	COUNTY A	COUNTY B	COUNTY C
1	X	6,000	3,000	2,000	1,000
1	Y	4,000	2,000	0	2,000
2	Z	5,000	1,000	500	3,500

Table 1a Survey respondents provided a list of hospitals to which their program provided inpatient services. To determine the number of patients to assign to each hospital and county, AHCA data was used. The number of patients served by each hospital for 2015 was summarized by county and linked to the hospitals reported by respondents to the survey.

Table 1b: AHCA Data				
RESPONDENT ID	TOTAL PATIENTS	COUNTY A (PROPORTION)	COUNTY B (PROPORTION)	COUNTY C (PROPORTION)
1	10,000	5,000 (.5)	2,000 (.2)	3,000 (.3)
2	5,000	1,000 (.2)	500 (.1)	3,500 (.7)

Table 1b Patients served by county were summed for each respondent. A proportion was generated by taking the number of patients treated from each county divided by the total number of patients.

Table 1c: Inpatient Capacity Calculation				
RESPONDENT ID	TOTAL PALLIATIVE CARE INPATIENTS (REPORTED IN SURVEY)	COUNTY A	COUNTY B	COUNTY C
1	1,000	1,000 (.5)= 500	1,000 (.2)=200	1,000 (.3)=300
2	750	750 (.2)=150	750 (.1)=75	750 (.7)=525
TOTALS		650	275	825

Table 1c These proportions were then multiplied by the number of inpatients that received palliative care as reported in the survey. To determine the overall capacity by county, numbers for each respondent were summed.

OUTPATIENT AND COMMUNITY/HOME-BASED CAPACITY

Researchers used a similar method to calculate the capacity for the outpatient and community/home-based palliative care programs. However, instead of using AHCA data to generate the proportions, researchers used county population data. Survey respondents from palliative care programs that provided outpatient and community/home-based palliative care identified which counties they served. The number of palliative care patients served, as reported on the survey, were proportionally assigned to the counties in which they provide services.

NEED

To determine the need for palliative care in Florida, mortality data was used. Deaths in 2015 were used to estimate the need for palliative care. A low estimate was calculated using deaths due to cancer, diabetes, Alzheimer's disease, coronary heart disease, cerebrovascular disease, chronic lower respiratory disease, and chronic liver disease. A high estimate was calculated using all deaths except accidents, homicides, and suicides. The final estimated need was calculated by taking the average of the low and high estimates.

While mortality data may not be the ideal way to determine need for palliative care in Florida, it did allow for a starting point. Other data, such as the Behavioral Risk Factor Surveillance System, which obtains information on chronic disease, is actually the lifetime prevalence, not the incidence. As a result, use of this data would overestimate the need in Florida. While mortality data is an underestimate of the need, it allows for the setting of a goal to achieve. This method is consistent with that of the California HealthCare Foundation mentioned above. This limitation in the methods was discussed with the PCAHC at the in-person meeting in January. All agreed that, while limited, this method would provide a good start to better understanding the gaps in palliative care in Florida.

SUFFICIENCY

To calculate the sufficiency for each county, the palliative care capacity was divided by the estimated need.

Survey Results

OUTREACH

The outreach process began by contacting each hospital and hospice/palliative care program by phone. Over 400 phone calls were placed to the hospital and hospice/palliative care programs identified in Florida. An explanation of the project was provided and willingness to participate was determined. The willing participants were then sent an email with a unique ID Number and a link to the survey. If the survey was not completed within one week, a follow up email was sent. If the survey was still not completed within one week of the follow-up email, a phone call was placed to the participant.

A total of 312 hospitals and 56 hospice/palliative care program were identified. Of the total number of hospitals and hospice/palliative care programs, 80 facilities mentioned they had a palliative care program and all agreed to participate and were subsequently emailed surveys. Of the 80 hospitals and hospice/palliative care programs that agreed to participate, 60 completed the survey, of which 45 reported actually providing palliative care to patients. Fifteen respondents initially stated by phone that their facility had a palliative care program, however, they reported on the survey that their facility actually did not provide palliative care (e.g., only provided hospice). Two respondents were removed from the analysis because of a discrepancy or missing information (final sample=43).

SUMMARY OF SURVEY RESPONSES

Of those that responded to the survey, 91% (n=39) reported serving patients in a hospital or inpatient setting, 33% (n=14) in an outpatient setting, and 33% (n=14) served palliative care patients in a community/home-based setting. Thirty-seven percent (n=16) of the programs reported serving patients across more than one setting.

The survey asked palliative care programs to report how many dedicated (half- to full-time) palliative care staff/specialists they employ from a variety of professional disciplines. Of the programs that responded, 91% (n=39) reported having at least one physician dedicated to palliative care, 70% (n=30) reported at least one dedicated advanced registered nurse practitioner (ARNP), and 47.1% (n=20) reported having two or more dedicated ARNPs.

Additionally, it was found that 56% (n=24) of programs had one or more social workers dedicated to palliative care. However, very few programs reported having one or more psychologists (n=2) or child life specialists (n=4) dedicated to palliative care.

The survey respondents reported treating a total of 50,032 palliative care patients in Florida during 2015 with individual programs seeing an average of 1,164 patients each. Of all patients treated, 85% (n=42,521) were cared for in an inpatient setting. However, only 37% (n=16) of programs reported that the number of patients treated put their program at maximum capacity. Furthermore, the survey asked respondents to report on the ages of the patients treated. Approximately 5% (n=2) of programs reported treating prenatal patients in 2015 and 28% (n=12) reported treating pediatric (0–17) patients. Palliative care during pre-natal care provides support to parents who discover during pregnancy that their baby has a life-limiting condition. Not surprisingly, 42 palliative care programs surveyed reported treating patients with some form of cancer. The average percentage of cancer patients treated among the programs surveyed was 39%.

Additional survey questions were asked about operations and funding. Of those who responded, 35% (n=15) reported being owned by a hospice program. Approximately 72% (n=31) of programs reported that they are funded by billing, 58% (n=25) by ongoing hospital support not including philanthropy, and 33% (n=14) from philanthropy/foundation(s)/grant(s). Approximately 77% (n=33) of respondents reported that their programs have increased their capacity (e.g., funding, staff, patients served) in 2015, whereas 5% (n=2) reported a decrease in capacity and 14% (n=6) of programs stated that their capacity was unchanged. Furthermore, 91% (n=39) of the programs stated they believe their palliative care programs will continue in the future.

capacity
need=
sufficiency
2015

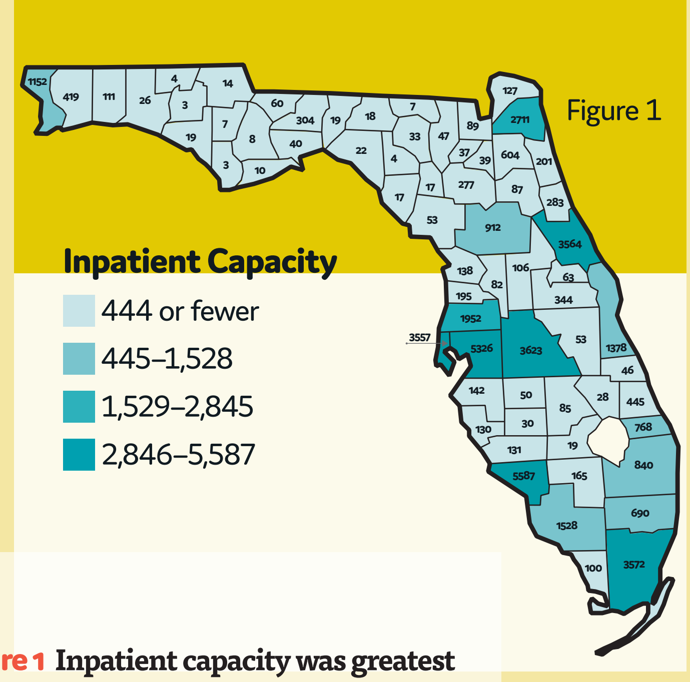


Figure 1 Inpatient capacity was greatest in Miami-Dade, Lee, Pinellas, Hillsborough, Polk, and Volusia counties.

Figure 2 Almost all of the counties in the Panhandle were in the lowest quartile for inpatient capacity and for the most part, outpatient capacity for palliative care was very low. The counties with the highest outpatient capacity were Pinellas and Orange.

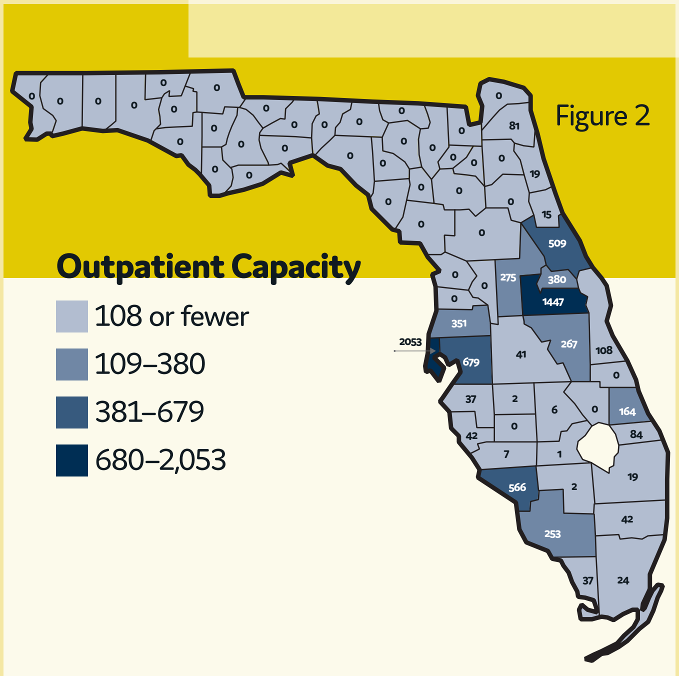
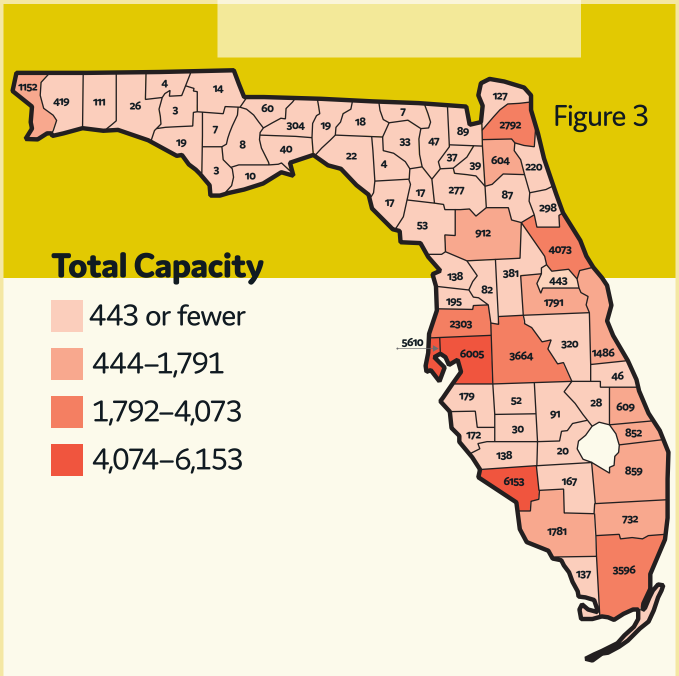


Figure 3 Because outpatient capacity for most counties was very low, total capacity looks very similar to the inpatient capacity map above (Figure 1).



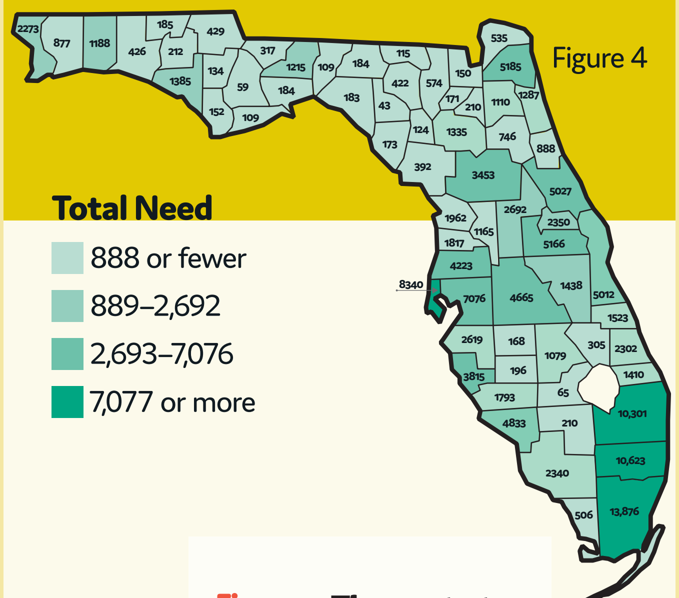


Figure 4 The greatest need for palliative care was identified to be in Pinellas County and the southeast: Miami-Dade, Broward, and Palm Beach.

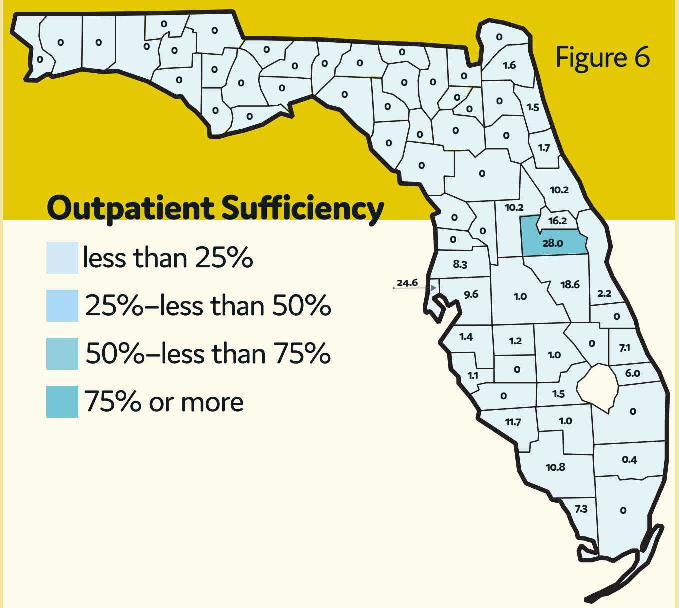


Figure 6 Outpatient sufficiency was less than 25% for all counties except Orange, which was at 28%. As described above, there was no outpatient palliative care identified throughout the panhandle.

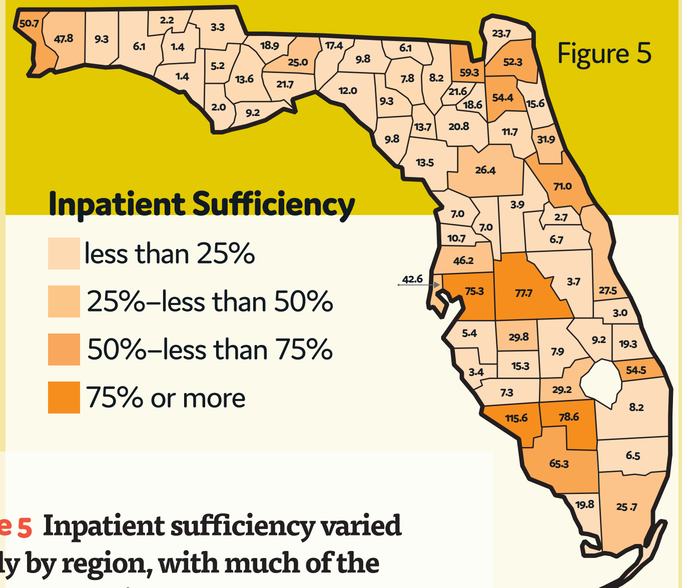
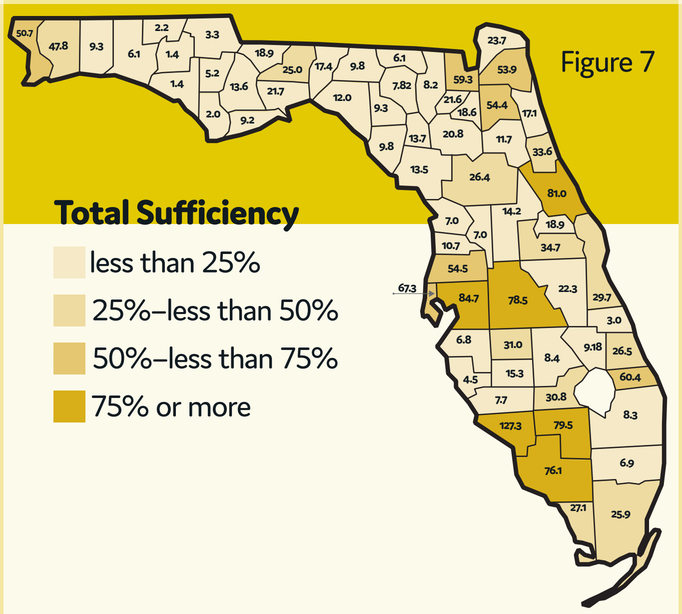


Figure 5 Inpatient sufficiency varied greatly by region, with much of the Panhandle having less than 25% sufficiency (exceptions: Escambia, Santa Rosa, and Leon). The Eastern part of the state, south of Volusia, also had low inpatient sufficiency. On the other hand, Hillsborough, Polk, Lee, and Hendry had greater than 75% inpatient sufficiency.

Figure 7 Because capacity for outpatient palliative care was limited, the findings for total sufficiency are similar to the inpatient results. Most of the panhandle had less than 25% sufficiency. Palliative care sufficiency for Collier County and Volusia increased above 75% when outpatient and inpatient capacity were combined, otherwise categories of sufficiency didn't change much from the inpatient results.



Need for Palliative Care Outcome Evaluation

Overarching outcomes for palliative care have been discussed in this report and include higher quality of life, better psychosocial support for the patient and caregiver, successful pain management, and reduced costs. Conducting an outcome evaluation on palliative care initiatives in Florida is a significant project that the PCAHC deferred to a later time when more resources could be dedicated to conducting such an evaluation.

Outcome evaluations of palliative care have been published and provide guidance to framing a study for Florida. One of the most recent studies reviewed eight studies and concluded that caregivers benefit from educational interventions that support dealing with pain management.[9]

Many outcome evaluations use the Palliative care Outcome Scale (POS), examining ten items involving symptoms, anxiety, fears, and well-being for both the patient and the caregiver. Other scales used are EQoL, which examines health in the areas of mobility, self-care, usual activities, pain or discomfort, and anxiety or depression. A third scale also used is the Herth Hope Index to assess hopefulness.[10]

Florida Statutes (Section 400.60501) mandates that licensed hospice programs submit outcome measures, demographic and diagnostic information to the Department of Elder Affairs each year.[11] Three mandatory outcome measures are required:

1. Percent of patients who reported severe pain who have a reduction of pain (5 or less on a 0–10 scale) by the fourth day of care in the hospice program
2. Percent of patients who report receiving the right amount of medicine to control pain
3. Percent of patients and/or family members who would recommend hospice to others based on the care the patient received

These hospice outcome measures are inadequate to evaluate palliative care initiatives. A valid outcome evaluation for palliative care in Florida would survey palliative care team members, their patients and their caregivers using at least one of the three scales already tested scientifically, such as those mentioned above. To be most useful, the evaluation study would involve palliative care programs in more than one area of the state, and would include questions about access to services as well as satisfaction with service delivery.

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9. Latter S, Hopkinson JB, Richardson A, et al. "How can we help family carers manage pain medicines for patients with advanced cancer? A system review of intervention studies." BMJ Supportive & Palliative Care 2016;6:263-275.

10. Higginson, IJ, Donaldson, N. Relationship between three palliative care outcome scales. Health and Quality of Life Outcomes, 2004, 2:68.

11. 2015 Report, Hospice Demographic and Outcome Measures, Office of Strategic Initiatives, Florida Department of Elder Affairs, February 8, 2016.

Relationship of Hospice to Palliative Care

Hospice is palliative care for end of life patients and their families. Patients over age 21 entering hospice agree to forego curative therapies and focus instead on quality of life therapies.

Medicaid patients age 21 or younger that are eligible for hospice services are not required to forego curative therapies as a condition of entering hospice, which is a provision of the Patient Protection and Affordable Care Act (PPACA), commonly referred to as "Concurrent Care."

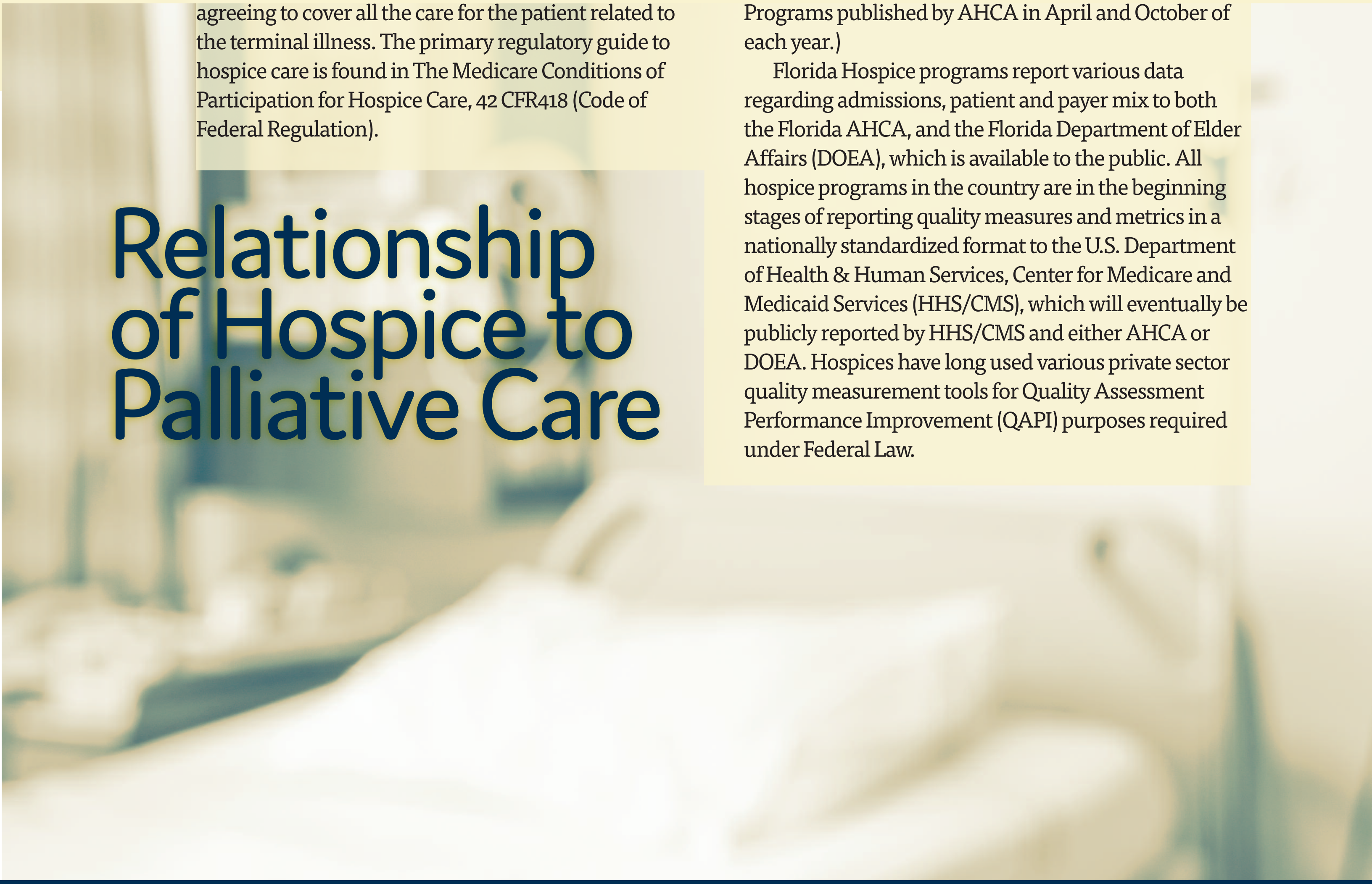
Hospice care provides medical services, emotional support, spiritual resources, and other forms of practical support for people who are diagnosed with a terminal disease or condition. Medicare and Medicaid both define hospice eligibility as someone with a life expectancy under the normal course of the disease or condition of six months or less. Part IV, Chapter 400 Florida Statutes, uses the same terminology but extends the prognosis to one year or less. Medicare and Medicaid are the primary payers for the Hospice Benefit. The Hospice Benefit is provided at one of four levels of care: Routine Home Care; Continuous Care; Respite Care; General Inpatient Care. Hospice programs provide this care on a risk-assumed, per diem payment basis, agreeing to cover all the care for the patient related to the terminal illness. The primary regulatory guide to hospice care is found in The Medicare Conditions of Participation for Hospice Care, 42 CFR418 (Code of Federal Regulation).

The goal of hospice care is to keep the patient comfortable and maximize his/her quality of life. Hospice treats the patient and family with a holistic approach, using a team of medical, psychosocial, and spiritual professionals, and other therapists and support staff, following a customized plan of care for each patient and family. Hospice care also helps family members and caregivers manage the practical details and emotional challenges of caring for a dying loved one.

Hospice programs offer services to patients wherever they reside or need the care. This includes residential homes, assisted living facilities, nursing homes, skilled nursing facilities, hospitals, and other unique institutional settings.

During calendar year 2015, Florida's 46 Hospice programs admitted 126,156 patients, across all 67 Florida Counties. Every portion of the state is served by one or more hospice programs. (Details by county are available in the Florida Need Projection for Hospice Programs published by AHCA in April and October of each year.)

Florida Hospice programs report various data regarding admissions, patient and payer mix to both the Florida AHCA, and the Florida Department of Elder Affairs (DOEA), which is available to the public. All hospice programs in the country are in the beginning stages of reporting quality measures and metrics in a nationally standardized format to the U.S. Department of Health & Human Services, Center for Medicare and Medicaid Services (HHS/CMS), which will eventually be publicly reported by HHS/CMS and either AHCA or DOEA. Hospices have long used various private sector quality measurement tools for Quality Assessment Performance Improvement (QAPI) purposes required under Federal Law.



Barriers to Delivering Quality Palliative Care Services

WORKFORCE ISSUES

A number of barriers exist in providing quality palliative care, the largest being the need for sufficient multi-disciplinary trained professionals. A robust palliative care team could include a physician, nurse, social worker, child life specialist, and chaplain, but some palliative care programs are able to provide quality care without a full team. The goal for establishing and maintaining a full palliative care team is lofty, but having a robust team results in more comprehensive services and reduced stress on the palliative care team.

FUNDING AND SUSTAINABILITY ISSUES

An equally important barrier is to establish a sustainable payment mechanism for palliative care services. A number of survey respondents reported using philanthropic support to supplement their funding for palliative care services, but continually searching for grants is not a sustainable model. Identifying the business case for palliative care and highlighting the value of the investment will assist administrators in recognizing that investing in palliative care at diagnosis results in substantial savings and higher quality of life as the disease progresses. Palliative care service models stress cost avoidance instead of the fee per service model. In the changing landscape of health care delivery, palliative care is cost effective and sustainable because it reduces significant costs, especially for hospital systems. Cost avoidance measures include reducing or eliminating re-admissions, emergency room over-utilization, and changing the trajectory of futile end of life treatments. As health care payers incentivize managing population health more efficiently, eliminating an intensive care unit hospitalization, for example, could be incorporated into member capitation rates to promote preventing costly expenditures.

PUBLIC PERCEPTIONS AND INCREASING DEMAND

Changing perceptions of palliative care is an important part of reducing barriers. Understanding that palliative care should start at diagnosis and exists as a concurrent part of the treatment protocol will transform patient understanding and demand for palliative care services. Palliative care involves more than pain management since it includes psychological and spiritual support to the patient and their caregivers. Palliative care approaches chronic diseases using phased-in methodologies. The first conversation is about relationship-building and the support needed by the patient and the family. Later, after support has been provided, health education about future decision-making takes place. End-of-life planning is incorporated when the patient is ready, and increased knowledge about the distinction between palliative care services and hospice is addressed by the palliative care team.

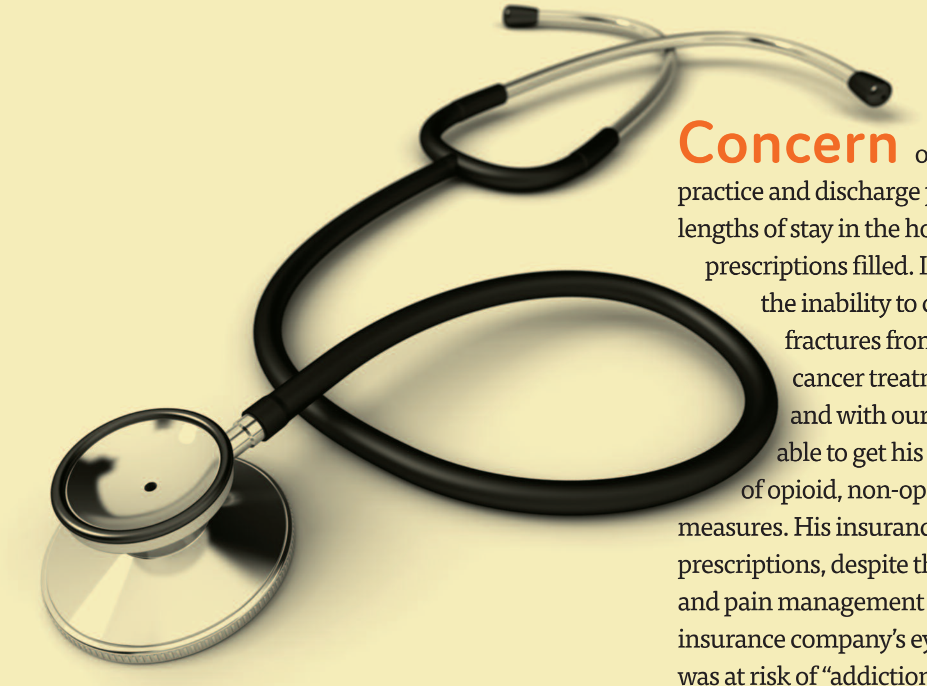
EXPANDING PUBLIC AWARENESS OF THE MEANING OF PALLIATIVE CARE

Adopting a common definition of the scope of palliative care is also important. As palliative care becomes more widely incorporated into complex disease management, some agencies may claim to provide palliative care when all they are doing is referring a patient to hospice at the appropriate time. This report helps illustrate the fact that referring to hospice is not equivalent to providing palliative care. Palliative care is not a common term, and some advocates have suggested changing the name to something more recognizable, such as supportive care services. The Palliative Care Ad Hoc Committee subject matter experts affirmed the continued use of the term palliative care as standards have been developed that reflect its complex set of service elements.

PAIN MANAGEMENT ISSUES

Further, it should be acknowledged that an additional barrier is concern over widely recognized misuse of prescription opioids. While palliative care includes pain management, it is not limited to that service. Having palliative care services in place will assist those chronically ill patients in obtaining necessary pain management, while distinguishing properly prescribed medications from substance abuse. Many palliative care practitioners also employ a wide variety of effective non-traditional methods of pain management/mitigation, such as yoga, meditation, and acupuncture or acupressure. Opioids are not the only option.

A Palliative Care Physician's Perspective



personal story

Concern over the opioid epidemic impacts my practice and discharge planning and can result in increased lengths of stay in the hospital due to challenges to getting prescriptions filled. I had a patient who was admitted due to the inability to control his pain because of repeated fractures from osteoporosis directly related to his cancer treatments. He was admitted to the hospital, and with our inpatient palliative care team we were able to get his pain under control with a combination of opioid, non-opioid, and non-pharmacological measures. His insurance company refused to fill the prescriptions, despite the oncologist, palliative care physician, and pain management physician intervening because in the insurance company's eyes, it was too much, too soon, and he was at risk of "addiction." Our hospital system filled it for him until we were able to work out with the insurance company what they would fill and when. They allowed the patient to have the regimen, but would not dispense the meds as written at the time of discharge "because he had just had the medications filled" due to his lack of pain control. Our team negotiated extensively with the insurance company. The patient is back at work and able to function and run his small business, now that his pain is controlled. While cancer free, he will have continued issues with pain from osteoporosis directly due to the treatments.

Strategies to reduce these barriers are discussed below in the Recommendations section.

Recommendations

The members of the Palliative Care Ad Hoc Committee focused on recommendations to advance palliative care service provision in Florida. The Committee stressed using national standards developed by various organizations and adopting them for Florida rather than re-creating Florida specific standards.

STRENGTHEN MINIMUM STANDARDS/EXPLORE CERTIFICATION

- **Standardize the definition of palliative care services in statute. Currently most of the statutes focus on hospice care (see Appendix D)**
- **Recommend the development of minimum standards that agencies have to meet in order for the agencies to say they provide palliative care**
- **Link with national authorities to endorse minimum standards consistent with national standards**
- **Increase standards to assure quality and strengthen consumer protection**
- **Promote multiple models of care recognizing that "one size does not fit all"**

INCREASE TRAINING OPPORTUNITIES

- **Increase university and hospital palliative medicine fellowships**
- **Endorse fellowship programs that already offer palliative medicine (UM, UM JFK, UF Jacksonville, Mayo Clinic, USF)**
- **Partner with universities or organizations to apply for grant monies to supplement funding for new fellowship programs**
- **Offer incentives for palliative care fellows who stay within the state of Florida**
- **Increase training programs for ARNPs, RNs, chaplains, social workers, and other relevant personnel**
- **Increase opportunities for medical/pharmacy, nursing, and social work students to participate in internships**

PROVIDE EDUCATION TO THE PUBLIC AND THE HEALTH CARE SECTOR

- **Establish a Florida website that also serves as a clearinghouse for information**
- **Pursue grant funding for research about palliative care and to educate other medical professionals and the general public about palliative care**
- **Develop partnerships with the private sector to promote palliative care, which ultimately reduces health care costs: Florida Council on Aging, Florida Chamber of Commerce, Chamber Foundation, Florida Health Care Coalition**

Appendixes

A. PALLIATIVE CARE AD HOC COMMITTEE MEMBERS

The Committee met by conference call twice and had a day-long face to face meeting.

Seth Berkowitz, LCSW, CCLS, Senior Patient Access Manager, Leukemia & Lymphoma Society, Florida Chapter

Audrey Brown, President, Florida Association of Health Plans

Gerardo Colon-Otero, MD, Professor of Medicine, Division of Hematology/Oncology, Mayo Clinic, Jacksonville, Florida

Leslie Gervase, MSN, BA, RN-BC, OCN, Patient Care Leader, American Cancer Society

Deadra Griffeth, RN, M.A., M.Div, Board Certified Chaplain, Regional Manager of Mission & Ministry, Florida Hospital, West Florida Region

Leonard R. Hock, Jr., DO, MACOI, CMD, Chair of Hospice and Chief Medical Officer, Florida Medical Directors Association, Harbor Palliative Care and Advanced Illness Management of TrustBridge Health

Suzanne Kelley, BPharm, CPH, Director, Pharmacy Services, Covenant Hospice, and Past President, Florida Pharmacy Association

Paul Ledford, President and CEO, Florida Hospice & Palliative Care Association

Blaine Pitts, MD, Medical Director, Palliative & Supportive Care, Pediatrics, Arnold Palmer Medical Center - Orlando Health

Myriam Rojas, Parent, Broward County

Colleen C. Tallen, MD, Medical Director, Palliative Care, Lee Memorial Health System

Department of Health Staff

Anna Likos, MD, MPH, Acting Deputy Secretary of Health

Shannon Hughes, Division Director, Community Health Promotion

Philip Cavicchia, PhD, Director, Public Health Research Section, Division of Community Health Promotion

Melissa Baniak, Public Health Research Section, Division of Community Health Promotion

Marion Banzhaf, Comprehensive Cancer Control Program Director, Division of Community Health Promotion

APPENDIX B. METHODS USED IN THE CALIFORNIA PALLIATIVE CARE PROJECT

The California Health Care Foundation developed a data visualization tool that illustrates the estimated need for palliative care in each California County among patients in their last year of life.

1. To identify the current palliative care **capacity** in California, researchers distributed a survey to inpatient hospitals to determine if they had a palliative care program and, if so, how many patients they serve annually. A survey was also distributed to all identified community-based palliative care programs to obtain the number of patients served annually and which counties they served. This information was used to determine capacity (making the assumption that the palliative care program is serving as many as possible). Note: Hospice programs were excluded from California's analysis because so few people used this service and, because it is usually used for less than one month, it doesn't remove the need for palliative care services.
2. To determine **need** researchers used mortality data. An estimate of the number of people in their last year of life requiring palliative care was based on the reported cause of death. A low estimate (death from seven specific conditions) and a high estimate (all deaths except accidents, homicides, or suicides) were calculated. The final estimated need for a county was the average of these two estimates.
3. **Sufficiency** was calculated by taking the palliative care capacity from step 1 and dividing it by the estimated need from step 2.

On their website, http://www.chcf.org/publications/2015/02/palliative-care-data, California displays the following information by county: population number, number of deaths, estimated palliative care need, annual capacity, and estimated sufficiency. They also provide the list of hospitals and community palliative care programs for each county, including their capacity.

APPENDIX C: RESOURCES ON PALLIATIVE CARE

Florida

Florida Hospice & Palliative Care Association The state hospice organization website www.floridahospices.org, and the consumer friendly website LetHospiceHelp.org, connect viewers with information and providers in 3 clicks or less. Each provider page lists the type of palliative care services provided if available.

National

Center to Advance Palliative Care (CAPC) Leading national clearinghouse supporting the National Palliative Care Registry™, a directory of palliative care services (GetPalliativeCare.org), and a national report card on the status of palliative care throughout the United Sta tes: www.capc.org.

American Academy of Pediatrics Released minimum standards for pediatric palliative care over 15 years ago: http://pediatrics.aappublications.org/content/106/2/351

Patient Quality of Life Coalition National organization to promote public policy to improve and expand access to palliative care: www.PatientQualityOfLife.org

American Academy of Hospice and Palliative Medicine Academic professional organization, promotes certification standards: www.Aahpm.org.

Hospice & Palliative Nurses Association National nursing organization: www.hpna.advacingexpertcare.org

National Hospice and Palliative Care Organization (NHPCO) Largest non-profit membership organization for programs and professionals providing palliative care: www.nhpco.org

APPENDIX D: FLORIDA STATUTES MENTIONING PALLIATIVE CARE

320.08058: Specialty license plates

The hospice license plate supports the Florida Association of Hospice and Palliative Care.

381.0303: Special needs shelters

Should allow palliative care provision.

Chapter 400: Nursing homes and related health care facilities

400.601: Definitions as used in this part the term:
(3) "Hospice" means a centrally administered corporation or a limited liability company that provides a continuum of palliative and supportive care for the terminally ill patient and his or her family.

(4) "Hospice care team" means an interdisciplinary team of qualified professionals and volunteers who, in consultation with the patient, the patient's family, and the patient's primary or attending physician, collectively assess, coordinate, and provide the appropriate palliative and supportive care to hospice patients and their families.

400.60501: Outcome measures; adoption of national initiatives; annual report
(1) No later than December 31, 2007, the Department of Elderly Affairs, in conjunction with the Agency for Health Care Administration, shall develop outcome measures to determine the quality and effectiveness of hospice care for hospices licensed in the state. At a minimum, these outcome measures shall include a requirement that 50 percent of patients who report severe pain on a 0-to-10 scale must report a reduction to 5 or less by the end of the 4th day of care on the hospice program.

400.609: Hospice services

409.815: Health benefits coverage; limitations
Social and economic assistance.

409.905: Mandatory medicaid services

409.906: Optional medicaid services

440.13: Medical services and supplies; penalty for violations; limitations
Worker's compensation.

Chapter 765: Health care advance directives

765.1103: Pain management and palliative care
Provide information on palliative care.

765.101: Definitions as used in this chapter:
"Health care" means care, services, or supplies related to the health of an individual and includes, but is not limited to, preventive, diagnostic, therapeutic, rehabilitative, maintenance, or palliative care, and counseling, service, assessment, or procedure with respect to the individual's physical or mental condition or functional status or that affect the structure or function of the individual's body.

765.102: Legislative findings and intent for purposes of this chapter:
(a) Palliative care is the comprehensive management of the physical, psychological, social, spiritual, and existential needs of patients. Palliative care is especially suited to the care of persons who have incurable, progressive illnesses.

(b) Palliative care must include:

1. An opportunity to discuss and plan for end-of-life care.
2. Assurance that physical and mental suffering will be carefully attended to.
3. Assurance that preferences for withholding and withdrawing life-sustaining interventions will be honored.
4. Assurance that the personal goals of the dying person will be addressed.
5. Assurance that the dignity of the dying person will be a priority.
6. Assurance that health care providers will not abandon the dying person
7. Assurance that the burden to family and others will be addressed
8. Assurance that advance directives for care will be respected regardless of the location of care
9. Assurance that organizational mechanisms are in place to evaluate the availability and quality of end-of-life, palliative, and hospice care services, including the evaluation of administrative and regulatory barriers.
10. Assurance that necessary health care services will be provided and that relevant reimbursement policies are available.
11. Assurance that the goals expressed in subparagraphs 1.–10. will be accomplished in a culturally appropriate manner.

(7) The Department of Elderly Affairs, the Agency for Health Care Administration, and the Department of Health shall jointly create a campaign on end-of-life care for purposes of educating the public. This campaign should include culturally sensitive programs to improve understanding of end-of-life care issues in minority communities.