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# ABOUT PALLIATIVE CARE

## Definition

According to the Center for Advancing Palliative Care (CAPC), palliative care is defined as, “specialized health care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of an illness, and it is based on need, not prognosis. The goal is to improve quality of life for both the patient and the family” (1).

Similarly, the National Consensus Project for Quality Palliative Care definition states, “Beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families and caregivers . Palliative care can be delivered in any care setting through the collaboration of many types of care providers. Through early integration into the care plan of seriously ill people, palliative care improves quality of life for both the patient and the family” (2).

## Why is it important for oncology patients?

Research has indicated that palliative care (inpatient, outpatient, and home-based) can not only improve the quality of life for oncology patients, but also decrease symptom burden.

- One meta-analysis found that palliative care was associated with statistically and clinically significant improvements in patient QOL at the 1- to 3-month follow-up and symptom burden at the 1- to 3-month follow-up. Additionally, palliative care was associated consistently with improvements in advance care planning, patient and caregiver satisfaction, and lower health care utilization (3).
- A study conducted at a Los Angeles medical center, found that those patients over 65 years old who received treatment from an inpatient palliative care team, averaged pain that was significantly different between baseline and two hours, as well as between 24 hours and hospital discharge. In addition, their average pain 10 days after discharge was significantly higher than pain at discharge. Cancer was the most common primary diagnosis at 35% (4).

- In a meta-analysis of outpatient and home-based palliative care studies, although there were methodological differences, interventions of early palliative care had many advantages including, “improvement in certain symptoms such as depression, improved patient quality of life, reduced aggressive care at the end of life, increased advanced directives, reduced hospital length of stay and hospitalizations, improved caregiver burden and better maintenance of caregiver quality of life and reduction in the medical cost of care as well as patient and family satisfaction” (5).
- For those patients with a potentially curable cancer, palliative care may not only improve their quality of life, but also improve their adherence to treatment. One study suggests that, “participation in a multidisciplinary QOL-directed intervention may be associated with an improved likelihood of patients with cancer completing their prescribed CR regimen without interruptions or dose reductions” (6).

***“By potentially improving quality of life (QOL), cost of care, and even survival in patients with metastatic cancer, palliative care has increasing relevance for the care of patients with cancer.” - American Society of Clinical Oncology (7)***

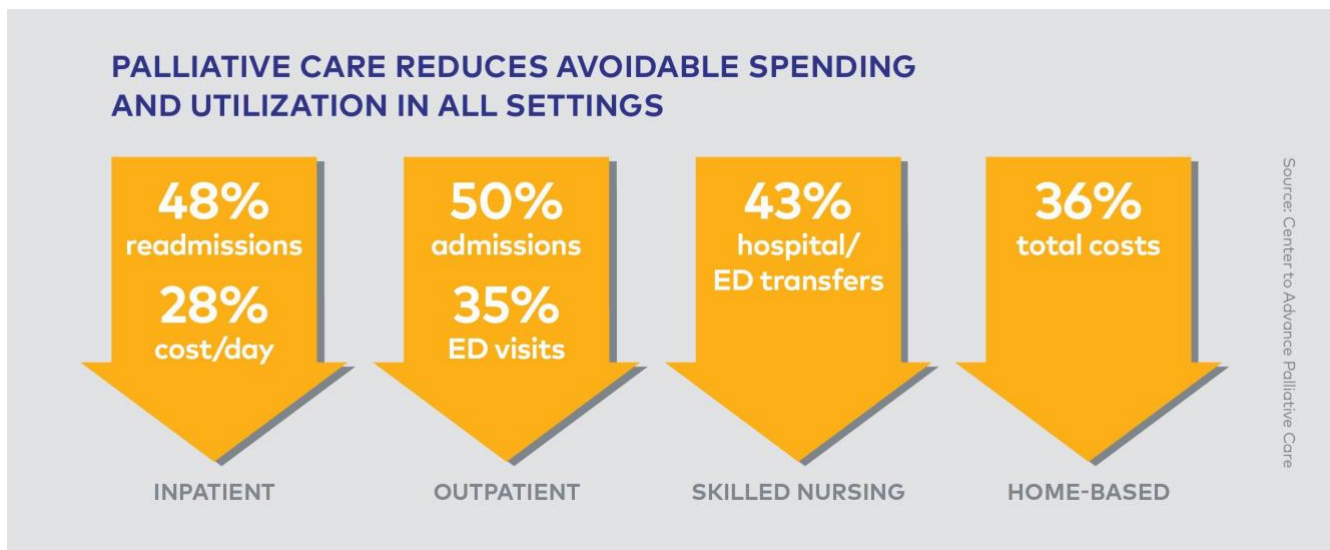
There is also significant evidence, that the quality of care an oncology patient receives can be greatly influenced by palliative care.

- In a comparison of cancer patients who were offered early palliative care consultation vs consultation after 3 months, those with earlier consultation had improved survival rates after one year (8).
- When cancer patients receiving palliative care were routinely assessed for fatigue, constipation, timely management of pain and constipation, and timely emotional well-being assessment they had higher levels of quality of life (9).

## Cost of Care

Palliative care has also been shown to substantially reduce the total cost of patient care.

- In an observational study of clinical and cost data from adult patients with an advanced cancer diagnosis admitted to five US hospitals from 2007 to 2011, earlier palliative care consultation during hospital admission was associated with lower cost of hospital stay for patients (10).
- A comparison study of early palliative care (more than 90 days prior to death) versus late palliative care (less than 90 days prior to death), found that among cancer patients who died, early referral to specialty palliative care is associated with less intensive medical care, improved quality outcomes, and cost savings at the end of life for patients with cancer (11).
- In a meta-analysis of 6 studies the authors found that early palliative care referrals (within 3 days of admission) reduce direct costs for hospitalized adults with life-limiting illness. They also concluded that estimates may be larger for primary diagnosis of cancer and more comorbidities compared with primary diagnosis of noncancer and fewer comorbidities (12).

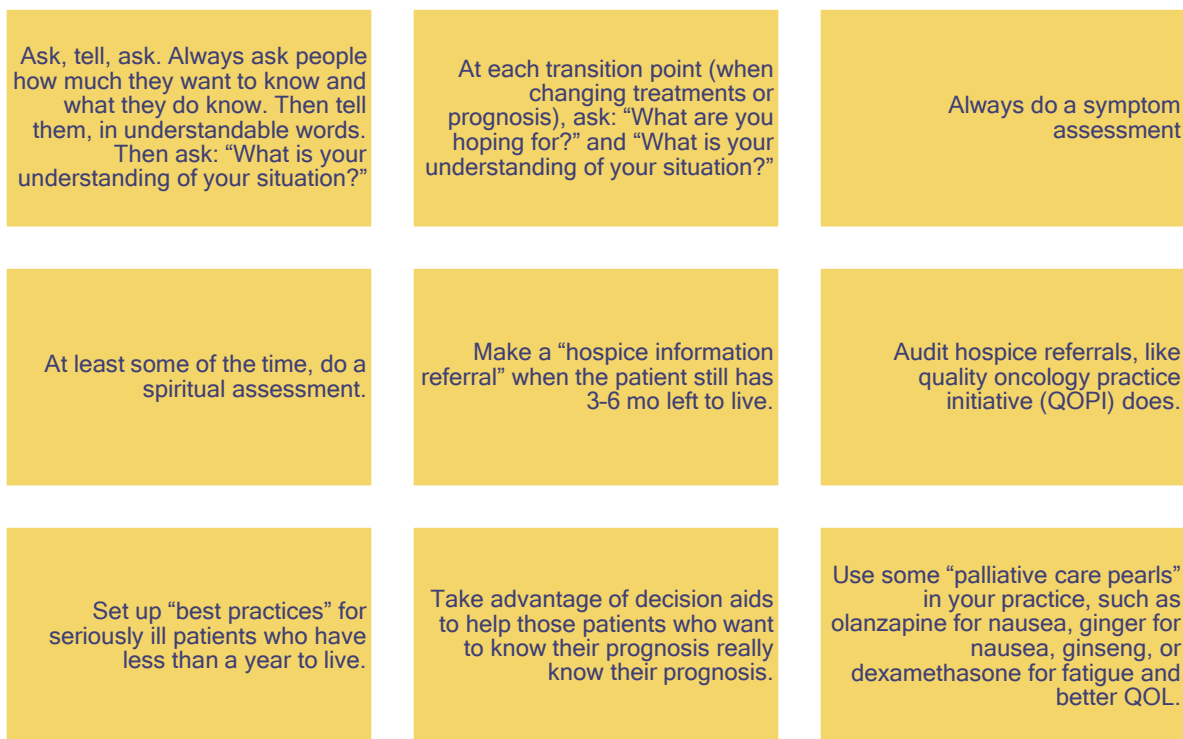


Source: <https://www.capc.org/about/palliative-care/>

## What is the role of the oncology provider?

In the article, “Integrating Palliative Care in Oncology: The Oncologist as a Primary Palliative Care Provider” the authors provide key components of Office-Based Primary Oncology Palliative Care (Figure 1). They emphasize that the basic principles of providing palliative care include, “frequent and honest communication, routine and systematic symptom assessment, integration of spiritual assessments, and early integration of specialized hospice and palliative care resources as a patient’s circumstances evolve” (13).

Figure 1



Palliative care provided concurrently with standard oncology care in patients with advanced cancer results in positive outcomes with regard to QOL, symptom relief, mood, patient satisfaction, advance care planning, and survival. Many professional societies, including the American Society of Clinical Oncology (ASCO), National Comprehensive Cancer Network (NCCN) and the European Society for Medical Oncology have made recommendations for early and integrated palliative care in the oncology setting (13.)

# PALLIATIVE CARE REFERRALS

In the “Integration of Palliative Care into Standard Oncology Care: American Society of Clinical Oncology Practice Guidelines Updates” published in 2016 the key recommendation given, stated (14):

“Patients with advanced cancer, whether inpatient or outpatient, should receive dedicated palliative care services, early in the disease course, concurrent with active treatment. Referring patients to interdisciplinary palliative care teams is optimal, and services may complement existing programs. Providers may refer caregivers of patients with early or advanced cancer to palliative care services.”

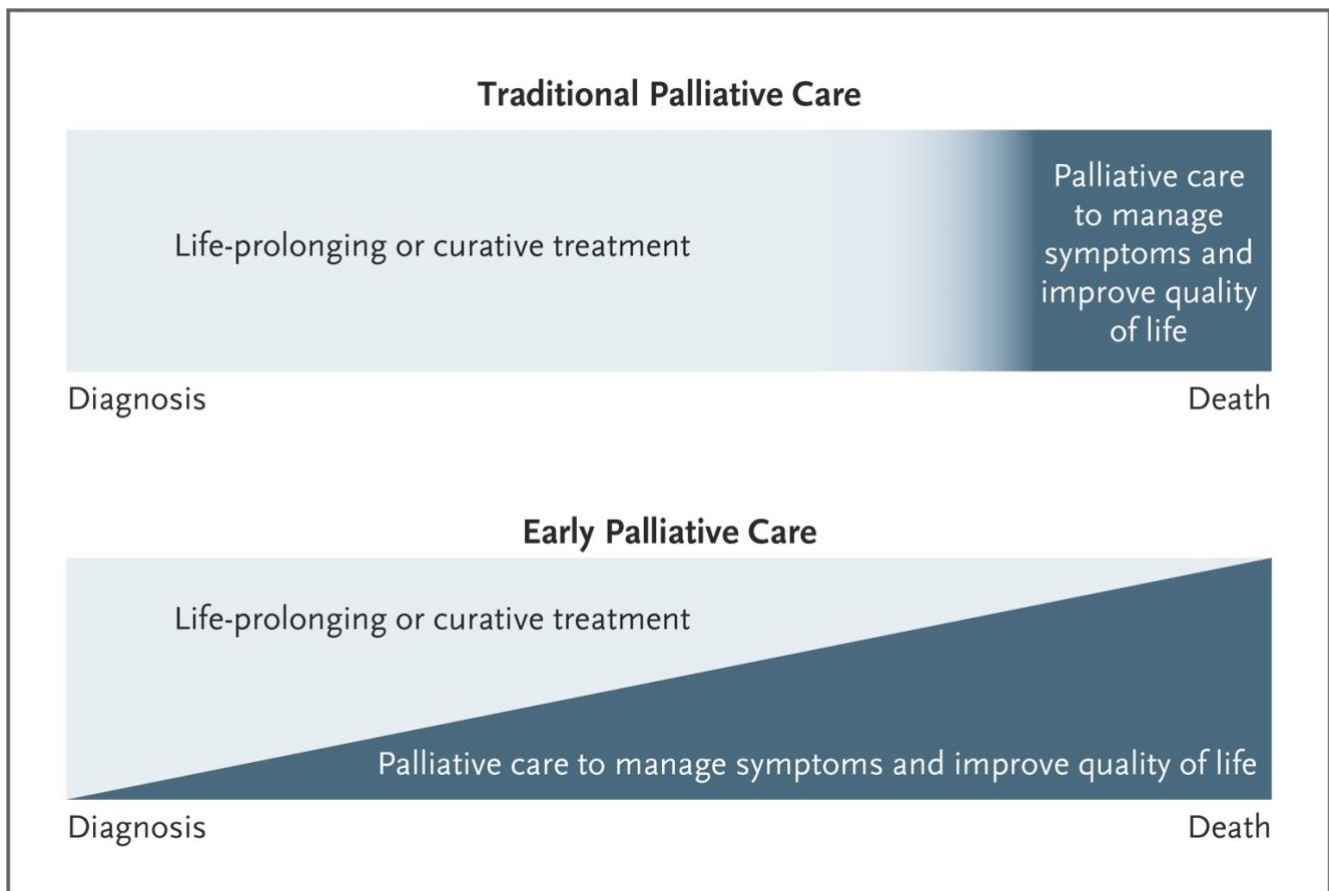
**They also included a specific recommendation re: newly diagnosed cancer patients:**

“For newly diagnosed patients with advanced cancer, the Expert Panel suggests early palliative care involvement within 8 weeks of diagnosis (type: informal consensus, benefits outweigh harms; evidence quality: intermediate; strength of recommendation: moderate).”

**Unfortunately, studies have shown that this is not currently the case:**

- In a study of 699 cancer specialists 48% reported referring >60% of patient to supportive care services, but mainly those with advanced cancer for symptom-related reasons. The main reasons reported for not referring patients included the ability to manage patient symptoms, lack of symptoms, or rapid decline of patient. It was also noted that psychosocial issues seldom prompted a referral (15).
- In a survey of 155 lung cancer physicians, 48% reported that they referred <25% of their patients to palliative care. The physicians’ reluctance to refer was explained by concern that involving palliative care would alarm patients and their families. However, those physicians who did refer patients, valued the time of palliative care dedicated to addressing complex issues (16).

- In a qualitative interview study of 74 medical oncologists from 3 academic cancer centers in the United States, 3 main barriers were identified for palliative care referrals. These included: “persistent conceptions of palliative care as an alternative philosophy of care incompatible with cancer therapy, a predominant belief that providing palliative care is an integral part of the oncologist's role, and a lack of knowledge about locally available services” (17).



**Figure 2. Traditional versus Early Palliative Care.**

In the traditional care model, palliative care is instituted only after life-prolonging or curative treatment is no longer administered. In the integrated model, both palliative care and life-prolonging care are provided throughout the course of disease. Adapted from the Institute of Medicine.

Source: <https://www.nejm.org/doi/full/10.1056/NEJMs1305469>



# INPATIENT PALLIATIVE CARE FOR ONCOLOGY PATIENTS IN NEBRASKA

In order to learn what palliative care services/programs look like for oncology patients in Nebraska, the Nebraska Cancer Coalition (NC2) partnered with CAPC. NC2 also completed phone interviews with cancer center and palliative care staff to gain insight of relevant topics to address in the report.

NC2 reached out to the 13 Commission on Cancer accredited cancer centers in the state and encouraged them to have their inpatient palliative care programs complete CAPC's National Palliative Care Registry. The registry includes data on program's structure and operations including program reach, patient populations, staffing, certification, patient screening, referrals, discharges, length of stay, documentation of preferences and goals of care. Seven of the thirteen participated in the registry, but only six submitted enough data to be analyzed.

## Staffing

The palliative care team varied by location and system, as evidenced by the data below.

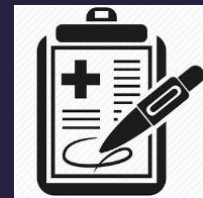
STAFFING DISCIPLINE	TEAM MAKE-UP	HEAD COUNT (average)	FTE (average)	PC certified (average)
Physician	67%	1.2	0.3	1
APRN	100%	3.5	2.7	1.8
PA	17%	3.5	2.7	---
RN	50%	0.7	0.5	0.3
Social Work	50%	1.2	1.1	0
Chaplain	50%	0.8	0.6	0
Nutritionist	17%	---	---	---
Pharmacist	17%	---	---	---
Hospice Liaison	17%	---	---	---
Case Manager	17%	---	---	---

## Program Features

- In regard to using national palliative care recommendations to aid program development:
  - 5 use the National Consensus Project (NCP) Clinical Practice Guidelines for Quality Palliative Care
  - 2 use the Joint Commission Advanced Certification for Palliative Care
  - 1 did not use any guidelines
  - 1 uses CAPC recommendations
- None of the programs measure patient and family satisfaction
- 33% provide team wellness activities (common examples include team retreats, regularly scheduled patient debriefing exercises, relaxation-exercise training, and individual referral for staff counseling)
- 17% utilize a trigger or standardized screening criteria to identify patients with palliative care needs, but it is not integrated with the Electronic Medical Record (EMR)
- Plans that the palliative care programs implement/utilize include:
  - 17% have a marketing plan
  - 17% have a bereavement plan (describes how they will assist the patients' family members during the period of transition before and following the death of their loved one)
  - 33% have a staff education plan (activities are offered to PC team members or other health professionals to help improve the quality of care provided to patients and their families)
  - 0% have a quality improvement plan (describes how a PC program evaluates its performance in delivering care, and outlines plans for improvements to program service offerings)
  - 50% have a strategic business plan
  - 17% have a multi-year budget
  - 67% have an orientation plan
  - 33% report not having any of these plans

## Consults, Documentation and Funding

- The top 3 reasons given by referring providers for the initial palliative care consult:
  - 100% symptoms
  - 100% establishing goals of care
  - 33% advance care planning
  - 33% withdrawal of treatment
  - 33% education or counseling support
  - 17% coordination of care
  - 50% end of life or hospice referral
- 66% report using a standardized consult note, of those the following are documented:
  - 100% goals of care
  - 100% surrogate decision maker
  - 100% life sustaining treatment preferences
  - 100% advance directive
  - 100% code status or DNR
  - 25% POLST (Physicians Orders for Life Sustaining Treatment)
  - 50% other (History & Physical, Symptom Management)
- The top 3 funding sources for inpatient palliative care program's budget:
  - 83% financial support from hospital
  - 50% fee for service billing
  - 17% grants
  - 17% not funded



# RECOMMENDATIONS

- All cancer centers and oncology practices are encouraged to integrate palliative care into their plans of care, if they have not already done so.
- All healthcare systems, oncology practices and community-based programs who provide palliative care, are encouraged to submit data to CAPC in order to establish a more comprehensive national and statewide palliative care database.
- All clinicians who prescribe cancer care are encouraged to utilize palliative care referrals as appropriate for their patients, as early in the treatment process as is feasible.
- NC2 or other similar statewide organizations are encouraged to convene training and networking of all the cancer centers and oncology practices for the sharing of best practices and peer reviewed resources.
- NC2 should network with other state cancer coalitions to track progress in expanding palliative care services for cancer patients nationally.
- NC2 should continue to maintain its relationship with CAPC and share current findings, trends, and resources with Nebraska's palliative care programs that serve cancer patients and their families.
- NC2 should continue to maintain its relationship with the Nebraska Palliative Care Advisory Council and share current palliative care findings, trends, and resources with Nebraska's palliative care programs that serve cancer patients and their families.
- NC2 is encouraged to include a Palliative Care poster or presentation in its 2020 Cancer Summit.

# SUGGESTED RESOURCES

- [American Society for Clinical Oncology - Palliative Care in Oncology](#)
  - Comprehensive library of ASCO's resources on palliative care, including links to meetings, videos from Cancer.Net, guidelines, and articles from *JCO* and *JOP*. All of the resources underscore the critical need to improve palliative care in oncology.
- [Center for Advancing Palliative Care \(CAPC\) Research in the Field](#)
  - Summary of some of the recent findings in palliative care research. Information is provided as an evidence base to inform program development, create presentations, write reports or grant proposals, and develop new research projects based on the current state of the evidence.
- [National Comprehensive Cancer Network's Clinical Guidelines on Palliative Care](#)
  - The NCCN Guidelines® are a comprehensive set of guidelines detailing the sequential management decisions and interventions that currently apply to 97 percent of cancers affecting patients in the United States. In addition, separate guidelines provide recommendations for some of the key cancer prevention and screening topics as well as supportive care considerations. The intent of the NCCN Guidelines is to assist in the decision-making process of individuals involved in cancer care—including physicians, nurses, pharmacists, payers, patients and their families—with the ultimate goal of improving patient care and outcomes.
- [National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for Quality Palliative Care, 4th edition](#)
  - Create a blueprint for excellence by establishing a comprehensive foundation for gold-standard palliative care for all people living with serious illness, regardless of their diagnosis, prognosis, age or setting.
  - The guidelines expand on the eight domains of palliative care in the 3rd edition and include clinical and organizational strategies, screening and assessment elements, practice examples, tools and resources.

# ACKNOWLEDGEMENTS

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CAPC for their collaboration and approval to use the data collected from Nebraska inpatient palliative care programs. The reader is encouraged to frequently visit the CAPC website for more information and updates about palliative care in the US.

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The Commission on Cancer accredited cancer centers for their willingness to connect us to the palliative care programs they work with.

The inpatient palliative care programs who participated in the National Palliative Care Registry and/or shared information regarding their programs.

## REFERENCES

1. CAPC (Center for Advancing Palliative Care). 2019. *About Palliative Care*. CAPC, New York City. <https://www.capc.org/about/palliative-care/>
2. National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4<sup>th</sup> edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. <https://www.nationalcoalitionhpc.org/ncp>
3. Kavalieratos D, Corbelli J, et al. Association Between Palliative Care and Patient and Caregiver Outcomes: A Systematic Review and Meta-analysis. *JAMA*, 2016 Nov 22; 316(20):2104-2114. <https://www.ncbi.nlm.nih.gov/pubmed/27893131>
4. Laguna J, Goldstein R, Allen J, Braun W, Enguidanos W, Enguidanos S. Inpatient palliative care and pain: pre- and post-outcomes. *J Pain Symptom Manage*. 2012;43(6):1051-1059. <http://www.ncbi.nlm.nih.gov/pubmed/22651948>
5. Davis MP, Temel JS, Balboni T, Glare P. A review of the trials which examine early integration of outpatient and home palliative care for patients with serious illnesses. *Ann Palliat Med*. 2015;4(3):99-121. <http://www.ncbi.nlm.nih.gov/pubmed/26231807>
6. Cheville AL, Alberts SR, Rummans TA, et al. Improving adherence to cancer treatment by addressing quality of life in patients with advanced gastrointestinal cancers. *J Pain Symptom Manage* 2015;50:321-327. <http://www.ncbi.nlm.nih.gov/pubmed/25975643>
7. Smith, TJ, Temin, S, Alesi, et al. American Society of Clinical Oncology Provisional Clinical Opinion: The integration of palliative care into standard oncology care. *J Clin Oncol*. 2012;30(8): 880-887. <https://ascopubs.org/doi/pdf/10.1200/JCO.2011.38.5161>
8. Bakitas MA, Tosteson TD, Li Z, et al. Early versus delayed initiation of concurrent palliative oncology care: patient outcomes in the ENABLE III randomized controlled trial. *J Clin Oncol*. 2015;33(13):1438-45. <http://www.ncbi.nlm.nih.gov/pubmed/25800768>
9. Kamal AH, Bull J, Stinson CS, Blue DL, Abernethy AP. Conformance with supportive quality measures is associated with better quality of life in patients with cancer receiving palliative care. *J Oncol Pract*. 2013;9(3):73-76. <http://www.ncbi.nlm.nih.gov/pubmed/23942504>
10. May P, Garrido MM, Cassel JB, et al. Prospective cohort study of hospital palliative care teams for inpatients with advanced cancer: earlier consultation is associated with larger cost-saving effect. *Clin Oncol*. 2015;33(25):2745-2752. <http://www.ncbi.nlm.nih.gov/pubmed/26056178>

11. Scibetta C, Kerr K, Mcguire J, Rabow MW. The costs of waiting: implications of the timing of palliative care consultation among a cohort of decedents at a comprehensive cancer center. *J Palliat Med.* 2016 Jan;19(1):69 - 75.  
<http://www.ncbi.nlm.nih.gov/pubmed/26618636>
12. May P, Normand C, Cassel JB, et al. Economics of Palliative Care for Hospitalized Adults With Serious Illness: A Meta-analysis. *JAMA Intern Med.* 2018;178(6):820-829.  
<https://www.ncbi.nlm.nih.gov/pubmed/29710177>
13. Rangachari, D., & Smith, T. J. (2013). Integrating Palliative Care in Oncology. *The Cancer Journal*, 19(5), 373-378. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4005332/>
14. Ferrell, B. R., Temel, J. S., Temin, S., Alesi, E. R., Balboni, T. A., Basch, E. M., . . . Smith, T. J. (2017). Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update. *Journal of Clinical Oncology*, 35(1), 96-112. <https://ascopubs.org/doi/full/10.1200/JCO.2016.70.1474>
15. Johnson, C., Girgis, A., Paul, C., & Currow, D. (2008). Cancer specialists palliative care referral practices and perceptions: Results of a national survey. *Palliative Medicine*, 22(1), 51-57. <https://www.ncbi.nlm.nih.gov/pubmed/18216077>
16. Smith, C. B., Nelson, J. E., Berman, A. R., Powell, C. A., Fleischman, J., Salazar-Schicchi, J., & Wisnivesky, J. P. (2011). Lung cancer physicians referral practices for palliative care consultation. *Annals of Oncology*, 23(2), 382-387. <https://doi.org/10.1093/annonc/mdr345>
17. Schenker, Y., Crowley-Matoka, M., Dohan, D., Rabow, M. W., Smith, C. B., White, D. B., Arnold, R. M. (2014). Oncologist Factors That Influence Referrals to Subspecialty Palliative Care Clinics. *Journal of Oncology Practice*, 10(2).  
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3948709/>