Bree Collaborative - Palliative Care Report and Recommendations - DRAFT
Updated: July 1, 2019

Background

People with serious or advanced illness often experience increases in symptoms coupled with a decrease in function. Serious illness is “*any condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress.*”[1] Traditional life-prolonging or curative care often does not meet a person’s range of needs as illness progresses and/or people near the end of life. Fragmented care delivery and frequent transitions between care settings, unmet symptoms such as pain, and responsibilities put on family members and other caregivers create undue stress and burden.[2] Many people who would prefer to remain at home experience high-intensity care often in a hospital setting.[3]

Palliative care fills the gap between intensive curative care and supportive care to better meet patient need. “*Palliative care focuses on expert assessment and management of* [symptoms including] *pain…assessment and support of caregiver needs, and coordination of care* [attending] *to the physical, functional, psychological, practical, and spiritual consequences of a serious illness. It is a person- and family-centered approach to care, providing people living with serious illness relief from the symptoms and stress of an illness.*”[4] While hospice care is given only to people with six months or less to live, palliative care can be offered alongside life-prolonging or curative care.[5] Many of the aspects of palliative care, including the patient needs described above, can and should be managed within primary care with referrals to specialty palliative care when patient need increases beyond the capacity of primary palliative care.

Provision of palliative care consistently shows improved outcomes for patients in both in- and out-patient settings.[6] Palliative care has been associated with reduction in symptom burden, higher satisfaction with care, higher referrals to hospice, and lower days in a hospital.[7,8] For patients with cancer, early delivery of palliative care has been associated with increased quality of life.[9] Use of supportive services like palliative care is associated with a move for end-of-life care from in-hospital to home.[10] Palliative care reduces caregiver stress and has been shown to reduce caregiver emotional and spiritual needs as well as increasing caregiver confidence.[11,12] Those who receive palliative care earlier on in the course of their disease have been shown to live longer when compared to those who started palliative care later.[13]

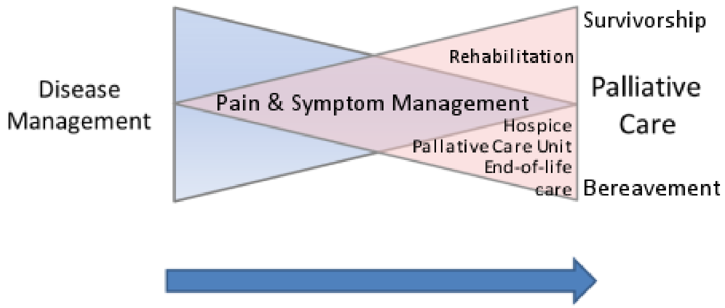
Oncology care has been an earlier adaptor of providing palliative care, but access remains inconsistent within oncology and especially for other diagnoses. Palliative care is largely offered in larger, not-for-profit, urban hospital settings.[14] In Washington State, 92% hospitals with greater than 300 beds have a palliative care program while 32% of those with fewer than 50 beds have a palliative care program.[15] Among oncology patients within the Veterans Administration, 52% received palliative care and those who received care did so for a median of 38 days prior to death.[16]

Barriers to palliative care referrals include lack of resources, lack of knowledge about existing resources, lack of knowledge about palliative care, provider reluctance to refer (e.g., due to fear of upsetting patients or being perceived as abandoning patients), reluctance of the patient and family to be referred, and restrictive criteria for referral to palliative care.[17] Further, the structures, processes, and definition of palliative care are often lacking. Poor or lack of reimbursement for palliative care services alongside life-prolonging and/or curative care also contributes to a lack of access.

Palliative care is focused on symptom management and for some is followed by rehabilitation and survivorship. For others, palliative care leads to hospice and end-of-life care as shown below in Figure X.

Figure X: Palliative Care Enhanced Model

Justis, Pat. Presentation to Palliative Care workgroup. April 12, 2019.



Recommendations

Successful palliative care programs have common elements including integrated teamwork, pain and physical symptom management, holistic care, caring providers, care that is timely and responsive, and patient and family preparedness.[18] The workgroup discussed needing to impact access and quality (e.g., specialty palliative care training for team members, 24/7 access to the care team) and the current state of palliative care in Washington State (e.g., limited access, variation based in organizational resources, definitions, patient experience) and developed recommendations to balance the ideal and the current state. Further, the workgroup chose to focus on the functions of palliative care rather than assign specific clinical roles to allow greater adaptability based on local resources. Focus areas include:

- Goals of care conversations.
- Defining palliative care using a standard definition and spreading awareness of palliative care.
- Cultural humility and clinical knowledge of the cultural needs and resources in the local community.
- Advance care planning conversations as outlined in the 2014 Bree Collaborative End-of-Life Care Report and Recommendations including appropriateness of an advance directive and Physician Orders for Life-Sustaining Treatment (POLST). Including coordination with appropriate resources (e.g., Honoring Choices).
- Defining primary and specialty palliative care and situations where each should be utilized.
    - **Primary palliative care**. Care delivered within primary and relevant sub-specialty care to meet physical, functional, psychological, practical, and spiritual consequences of a serious illness. Providers should refer patients to specialty palliative care when needs cannot be met within primary palliative care.
    - **Specialty palliative care**. An interdisciplinary team that includes or has access to a care coordination function and is able to meet medical, psychological, and spiritual care needs. Access (e.g., telemedicine) to 24/7 specialty expertise is highly recommended. The National Consensus Project for Quality Palliative Care National Coalition for Hospice and Palliative Care Clinical Practice Guidelines for Quality Palliative Care, 4th edition eight domains outline the ideal components of palliative care against which programs can compare.
- Sustainability of palliative care through a per member per month palliative care benefit for the diverse specialty palliative care services that support seriously ill patients.
- Defining a patient population for whom palliative care will offer benefit by adapting the criteria of the American Academy of Hospice and Palliative Medicine: Payment Reforms to Improve Care for Patients with Serious Illness Patient and Caregiver Support for Serious Illness (PACSSI) criteria.

Recommendations by Stakeholder Group

Patients and Family Members

- Know who your primary care provider is and how to reach them.
- Talk about your goals of care with your provider or care team.
- If applicable, know who to contact on your palliative care team with questions or urgent issues.
- **Advance Care Planning.** Think about the type of care you would want at the end of life. Have a conversation with your family members or other caregivers about what you would want. You should also have a conversation with your care team about your wishes, goals, and values for end-of-life care that includes caregivers and the individual designated as your durable power of attorney for health care.
    - Talk about how family members or other caregivers should implement the care plan if you are unable to express your wishes.
    - We recommend that you complete:
        - An advance directive that stipulates specific treatment preferences (if known and applicable to the situation),
        - A durable power of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate should have in decision-making, and
        - A written personal statement that articulates your values and goals regarding end-of-life care.
    - A Physician Orders for Life-Sustaining Treatment (POLST) form may be appropriate. These are completed with your physician and/or clinical team.
- Have conversations early on in disease progression about your wishes for hospital visits and medical intervention. Conversations should include risks and benefits of hospitalization and may include filling out a POLST. As part of these conversations, think about the type of care that you would not want (e.g., feeding tubes). Information from Choosing Wisely and Consumer Reports on feeding tubes can be found here.
- Be sure that you and your family or other caregivers understand red flags that may mean you need to go to the hospital and under what conditions you may not want to receive care in the hospital setting.
- Talk about the potential need for a higher level of care (e.g., more help at home) if care needs are greater than can be safely managed. Conversations should include financial as well as medical concerns.
- Connect to community resources or state resources that can help plan for future and increasing care needs including respite care.
- **For Caregivers**. Caregiving can be stressful. Talk to your or your partner/family member's provider about your needs as a caregiver. More information specific to Alzheimer's disease but relevant to many types of caregiving is here.

Specialty Palliative Care

- **Patient population.** Develop a common definition for which patients are considered to have a serious illness. This definition should be shared within the organization and with health plans.
- **Community.** Understand the local community characteristics (e.g., language needs, religious background, cultural background) and local community resources.

- **Interdisciplinary team.** Define the members of the interdisciplinary team to meet a patient's medical, psychological, and spiritual care needs. The interdisciplinary team should:
    - Designate a leader, not necessarily a physician.
    - Hold regular team meetings as defined by the team (e.g., weekly, bi-weekly).
    - Offer a care management function, either conducted by an individual or shared between members.
- **Inclusions in first visit.**
    - **Goals of care.** For all patients, discuss their goals of care. Document in the medical record. Goals of care should be reassessed regularly as they may change over time.
    - **Cognitive impairment:** Assess for and address cognitive impairment, if present, using the recommendations outlined in the 2017 Bree Collaborative Alzheimer's Disease and Other Dementias Report and Recommendations.
    - **Medical care.** Assess and manage physical symptoms of serious illness and quality of life.
        - Communicate with the patient's primary care provider, if possible.
        - Assess for sleep quality and sleep disturbance.
        - Review and manage medications.
    - **Caregiver needs**. Assess caregiver stress, capacity, and support.
    - **Behavioral health**. Assess and manage psychological symptoms.
        - Explain to patients the purpose of screening for depression, suicidality, alcohol misuse, anxiety, and drug use including the safety and security of the information. Screen for the following using a validated instrument:
            - Depression (e.g. Patient Health Questionnaire-2, PHQ-3 and/or PHQ-9) and anxiety (e.g., Generalized Anxiety Disorder-2). Follow guidelines within the 2017 Bree Collaborative Behavioral Health Integration Report and Recommendations, or more recent if available.
            - Suicidality (e.g. ninth question of the PHQ-9, first and second questions of the Columbia Suicide Severity Rating Scale (C-SSRS), the Ask Suicide-Screening Questions (ASQ) as well as current plans and any past attempts). If suicide risk is detected, follow guidelines within the 2018 Bree Collaborative Suicide Care Report and Recommendations, or more recent if available.
            - Alcohol misuse (e.g., AUDIT-C) and drug use (e.g., ASSIST, DAST-10, single item cannabis and other drug use questions). If alcohol misuse or illicit drug use is detected, follow guidelines within the 2015 Bree Collaborative Addiction and Dependence Treatment Report and Recommendations, or more recent if available following the Screening, Brief Intervention, and Referral to Treatment protocol.
    - **Spiritual care needs**. Assess and discuss spiritual care needs. Ideally this is done through a board certified chaplain with specific training in hospice and palliative care medicine, when available.

        - **Other needs**. Discuss practical consequences of a serious illness such as difficulty with activities of daily living. Connect with community resources, as needed.
        - **Advance care planning**. Conduct advance care planning conversations as outlined in the 2014 Bree Collaborative End-of-Life Care Report and Recommendations.
            - Document advance care planning discussions with easily understandable and culturally appropriate advance directives that include: a living will (also called a health care directive) that stipulates specific treatment preferences (if known and applicable to the situation), a durable power of attorney for health care that names a surrogate and indicates the amount of leeway the surrogate should have in decision-making, and a written personal statement that articulates the patient's values and goals regarding end-of-life care.
- **Ongoing care**. Assess and address medical, behavioral health, and spiritual care needs as appropriate.
- **Urgent Issues.** Make sure that patients and their family caregivers know who and how to contact on the team with questions or urgent issues.
    - Access to the care team or to other specialty expertise that is connected to the care team 24 hours a day, 7 days a week is highly recommended, but not required as this may not be feasible in all areas.
    - Discuss possible red flags that may necessitate admission to an acute care setting as well as risks and benefits of hospitalization.
    - Discuss how to plan and prepare for a potential inpatient stay including risks and benefits of a hospitalization and when the patient may want to be hospitalized and when they may not want care in a hospital setting.

Primary Care Providers and Sub-specialty Providers

- For all patients with serious illness, discuss goals of care. Document in the medical record.
- Assess and manage physical and psychological symptoms.
- Make sure that patients know who and how to contact on the team with questions or urgent issues.
- If needs become greater than can be managed within primary care, refer to specialty palliative care.

Health Plans

- Offer a per member per month palliative care benefit for seriously ill patients using an agreed-upon identification strategy.

Health Care Authority

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Goals of Care Conversations

Goals of care conversations should be part of all clinical encounters involving serious illness. A goals of care intervention targeted to both patients and clinicians has been associated with a significant increase in goals of care conversations occurring, being documented in the medical record, higher-quality conversation, and concordance between patient goals and actual care in patients with stable goals when compared with usual care.[19]

Per Member Per Month Benefit

TBD

Patient Population

The workgroup acknowledges that reimbursement based on a per member per month basis requires a defined population. However, patient populations vary region by region. Many other organizations have worked to define serious illness populations to whom provision of palliative care is warranted including the American Academy of Hospice and Palliative Medicine that developed the Payment Reforms to Improve Care for Patients with Serious Illness Patient and Caregiver Support for Serious Illness (PACSSI) bundled payment model including defining a serious illness population. The workgroup suggests use of this common definition.

Table X: PACSSI Eligibility and Tiering Criteria

Tier	Diagnosis of Serious Illness (one of the below)	Function (one of the below)	Health Care Utilization
Tier 1: Moderate Complexity	One of the specified diseases, disorders, or health conditions in Table 2 below Three or more serious chronic conditions*	Non-Cancer: PPS of ≤60% or ≥ 1 ADLs or DME order (oxygen, wheelchair, hospital bed) Cancer: PPS of ≤70% or ECOG ≥2 or ≥ 1 ADL or DME order (oxygen, wheelchair, hospital bed)	One significant health care utilization in the past 12 months, which may include: - ED visit - Observation stay - Inpatient hospitalization Note: This criterion may be waived under certain circumstances specified below.
Tier 2: High Complexity	Same as above, Excluding dementia as the primary illness	Non-Cancer: PPS of ≤50% or ≥ 2 ADLs Cancer: PPS of ≤60% or ECOG ≥3 or ≥ 2 ADLs	Inpatient hospitalization in the past 12 months AND one of the following - ED visit - Observation stay - Second Hospitalization Note: This criterion may be waived under certain

			circumstances specified below.

Diagnoses
Option 1: A diagnosis of one of the following would meet the serious illness criterion:

- Metastatic Cancer
- Pancreatic, Gastrointestinal, Lung, Brain, Hematologic, or Ovarian cancers
- Heart Failure with Class III or IV level function under the New York Heart Association (NYHA) Functional Classification
- Heart Failure with a Left Ventricular Assist Device (LVAD)
- Advanced Pulmonary Disease (Pulmonary Hypertension, Chronic Obstructive Pulmonary Disease, Pulmonary Fibrosis)
- Advanced Dementia with stage 6 or 7 using the Functional Assessment Staging Tool (FAST) or ≥ 2 ADLs*
- Progressive Neurologic Disorder (e.g. Cerebrovascular Accident (CVA), Parkinson’s Disease, Amyotrophic Lateral Sclerosis, Progressive Supranuclear Palsy)
- Hepatic Failure (Cirrhosis)
- Stage IV or V Renal Disease
- Protein-Calorie Malnutrition
- Cachexia
- Hip Fracture (with functional decline)

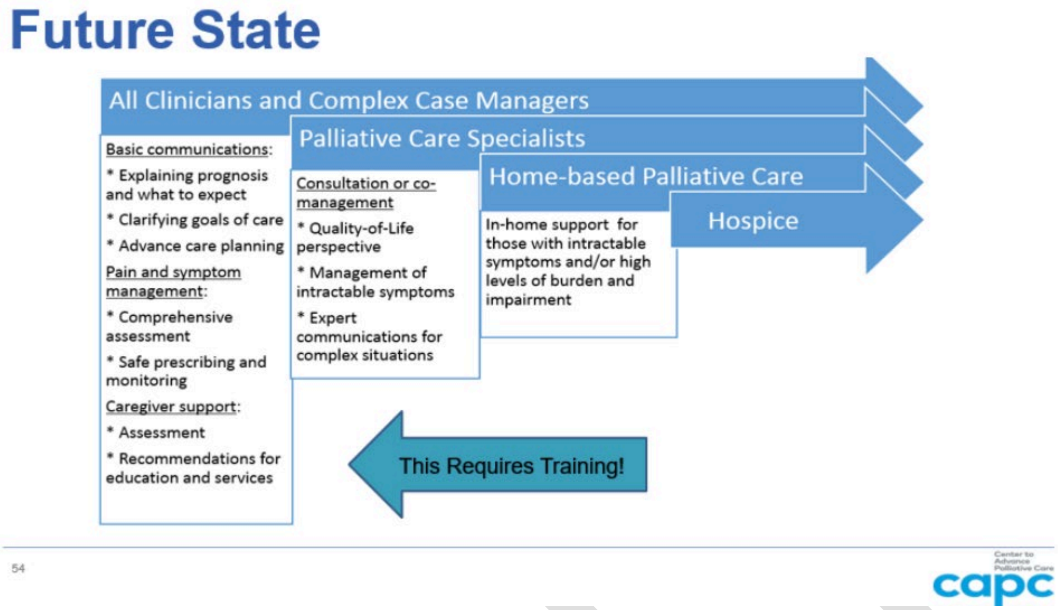
Option 2 Diagnoses of three or more serious chronic conditions would also allow a patient to meet the serious illness criterion.
* Dementia as the primary illness would be confined to the moderate complexity group, as the rate of decline is often slow, and functional limitations occur significantly earlier in the course of an illness.

Work within Washington State

Justis, Pat. Presentation to Palliative Care workgroup. April 12, 2019.

Required element	Description
Interdisciplinary team	Have regular interdisciplinary team meetings.
Assessment and management of symptoms	Initial & ongoing, including physical and non-physical symptoms
Provider & care team education	Staff has sufficient & appropriate training relevant to roles on the team
Offer patient & family centered advanced care planning and goals of care	Have a policy/process to support patients in creating an advance directive if they do not have one

Care is accessible	May include access after hours, community-based resource support and services, care coordination, and continuity of care



Future State

All Clinicians and Complex Case Managers

Palliative Care Specialists

Home-based Palliative Care

Hospice

Basic communications:
* Explaining prognosis and what to expect
* Clarifying goals of care
* Advance care planning
Pain and symptom management:
* Comprehensive assessment
* Safe prescribing and monitoring
Caregiver support:
* Assessment
* Recommendations for education and services

Consultation or co-management
* Quality-of-Life perspective
* Management of intractable symptoms
* Expert communications for complex situations

In-home support for those with intractable symptoms and/or high levels of burden and impairment

This Requires Training!

Quality Metrics

Source[20]

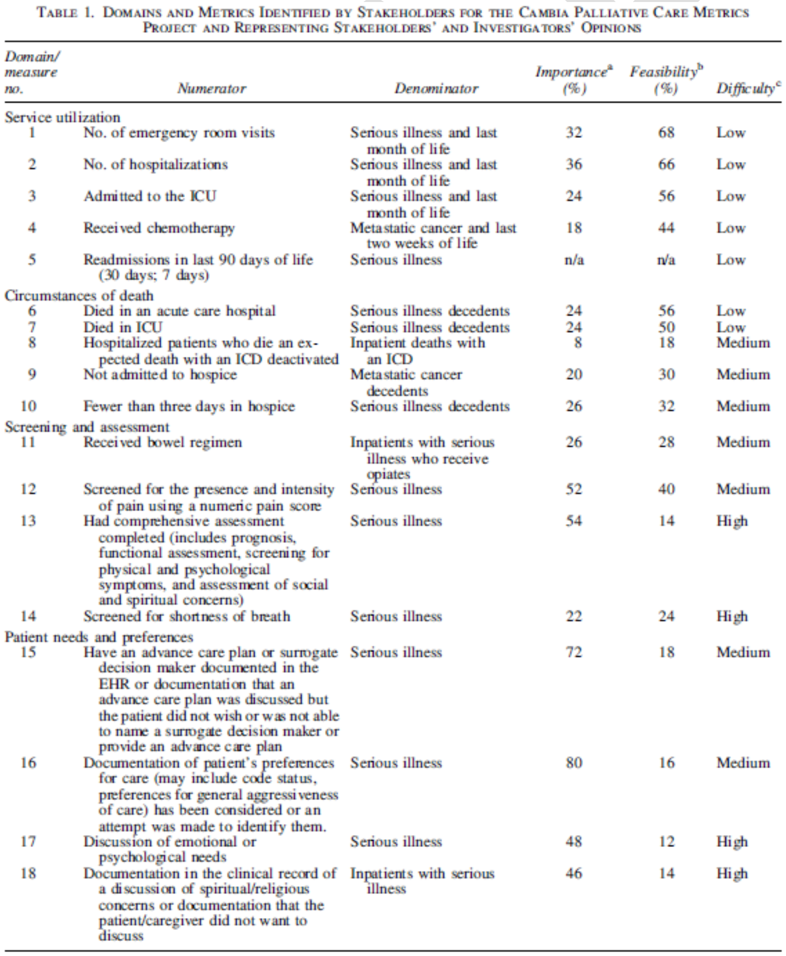


TABLE 1. DOMAINS AND METRICS IDENTIFIED BY STAKEHOLDERS FOR THE CAMBIA PALLIATIVE CARE METRICS PROJECT AND REPRESENTING STAKEHOLDERS' AND INVESTIGATORS' OPINIONS

Domain/ measure no.	*Numerator*	*Denominator*	*Importance*[a] *(%)*	*Feasibility*[b] *(%)*	*Difficulty*[c]
Service utilization					
1	No. of emergency room visits	Serious illness and last month of life	32	68	Low
2	No. of hospitalizations	Serious illness and last month of life	36	66	Low
3	Admitted to the ICU	Serious illness and last month of life	24	56	Low
4	Received chemotherapy	Metastatic cancer and last two weeks of life	18	44	Low
5	Readmissions in last 90 days of life (30 days; 7 days)	Serious illness	n/a	n/a	Low
Circumstances of death					
6	Died in an acute care hospital	Serious illness decedents	24	56	Low
7	Died in ICU	Serious illness decedents	24	50	Low
8	Hospitalized patients who die an expected death with an ICD deactivated	Inpatient deaths with an ICD	8	18	Medium
9	Not admitted to hospice	Metastatic cancer decedents	20	30	Medium
10	Fewer than three days in hospice	Serious illness decedents	26	32	Medium
Screening and assessment					
11	Received bowel regimen	Inpatients with serious illness who receive opiates	26	28	Medium
12	Screened for the presence and intensity of pain using a numeric pain score	Serious illness	52	40	Medium
13	Had comprehensive assessment completed (includes prognosis, functional assessment, screening for physical and psychological symptoms, and assessment of social and spiritual concerns)	Serious illness	54	14	High
14	Screened for shortness of breath	Serious illness	22	24	High
Patient needs and preferences					
15	Have an advance care plan or surrogate decision maker documented in the EHR or documentation that an advance care plan was discussed but the patient did not wish or was not able to name a surrogate decision maker or provide an advance care plan	Serious illness	72	18	Medium
16	Documentation of patient's preferences for care (may include code status, preferences for general aggressiveness of care) has been considered or an attempt was made to identify them.	Serious illness	80	16	Medium
17	Discussion of emotional or psychological needs	Serious illness	48	12	High
18	Documentation in the clinical record of a discussion of spiritual/religious concerns or documentation that the patient/caregiver did not want to discuss	Inpatients with serious illness	46	14	High

Colorado, Illinois, and Rhode Island include the HEDIS Care for Older Adults metric as a performance-based measure in their MLTSS or financial alignment demonstration contracts.

o HEDIS measure is defined as "the percentage of beneficiaries 66 years and older who have the advanced care planning, medication review, functional status assessment, and pain screening in one measurement year."

Goals of American Academy of Hospice and Palliative Medicine: Payment Reforms to Improve Care for Patients with Serious Illness:

- Reducing pain and suffering patients experience due to their illnesses
- Reducing stresses and physical burdens on caregivers that can create or worsen their health problems
- Enabling caregivers to remain employed and productive
- Reducing the number of times patients visit Emergency Departments for symptoms or exacerbations of their health conditions
- Reducing the number of hospital admissions for exacerbations or complications of the patients' health conditions
- Reducing the use of emergency transportation for ED visits and hospital admissions;
- Reducing the use of intensive care beds during hospital stays
- Reducing unnecessary office visits to specialists for routine follow-up care
- Reducing unnecessary and duplicative laboratory testing and imaging services
- Reducing the use of low-value treatment services and medical technologies that do not extend the patient's life and may worsen the patient's quality of life
- Avoiding the costs of maintaining medical devices that do not support or improve the patient's quality of life
- Reducing the use of expensive post-acute care services such as skilled nursing facilities and home health services to address post-acute care needs that can be addressed at lower cost

ECOG Performance Status

Developed by the Eastern Cooperative Oncology Group, Robert L. Comis, MD, Group Chair.*

GRADE	ECOG PERFORMANCE STATUS
0	Fully active, able to carry on all pre-disease performance without restriction
1	Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work
2	Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours
3	Capable of only limited self-care; confined to bed or chair more than 50% of waking hours
4	Completely disabled; cannot carry on any self-care; totally confined to bed or chair
5	Dead

*Oken M, Creech R, Tormey D, et al. Toxicity and response criteria of the Eastern Cooperative Oncology Group.*Am J Clin Oncol.* 1982;5:649-655.

Source: https://ecog-acrin.org/resources/ecog-performance-status

Appendix C: Guideline and Systematic Review Search Results

	Year	*Title*	*Summary*
AHRQ: Research Findings and Reports	2017	Assessment Tools for Palliative Care	We identified more than 150 assessment tools addressing most domains of palliative care, but few tools addressed the spiritual, structure and process, ethical and legal, or cultural domains, or the patient-reported experience subdomain. While some data on the psychometric properties of tools exist, the responsiveness of different tools to change has largely not been evaluated. Future research should focus on: (1) developing or testing tools in palliative care populations for domains with few or no tools, (2) evaluating responsiveness of tools for all domains, and (3) further studying the use of palliative care tools in clinical care and as quality indicators.
	2016	Home-Based Primary Care Interventions	The services included in the HBPC interventions varied widely, and no identifiable combination was related to more positive outcomes. We identified four studies that evaluated the addition of specific services. Combining palliative care and primary care home visits increased the likelihood of death at home (2 studies; low strength of evidence), while studies on adding caregiver support (1 study) or transitional care (1 study) to HBPC were rated as having insufficient evidence.
	2014	Decision Aids for Advance Care Planning	Numerous decision aids are widely available but not represented in the empirical literature. Of the 16 published studies testing decision aids as interventions for adult ACP, most were proprietary or not openly available to the public. Decision aids tend to be constructed for the general population or for disease-specific conditions for narrower decision choices. Designing decision aids that are responsive to diverse philosophical perspectives and flexible to change as people gain experience with their personal illness courses remains an important concern. Future directions for effort include further research, training of ACP facilitators, dissemination and access, and the potential opportunities that lie in social media or other technologies.
	2012	Closing the Quality Gap Series: Improving Health Care and Palliative	We found that evidence was strongest (moderate strength of evidence) for interventions for pain, and for the targets of communication and decision making and continuity for selected outcomes. While a few high- and medium-quality, well-designed health care and palliative care interventions have been conducted to improve outcomes for patients with advanced and serious illness, this report highlights the continued

		Care for Advanced and Serious Illness	presence of variable findings, quality deficiencies, vaguely defined interventions, and variable outcome measurement tools and reporting in much of this intervention literature. The evidence has a number of gaps, including few studies in the hospice setting or pediatrics.
	2010	A Review of Quality of Care Evaluation for the Palliation of Dyspnea	Systematic reviews identified only 3 existing quality measurement sets that included quality measures for dyspnea care. The existing dyspnea quality measures reported by retrospective evaluations of care assess only 4 aspects: dyspnea assessment within 48 hours of hospital admission, use of objective scales to rate dyspnea severity, identification of management plans, and evidence of dyspnea reduction...The panel recommended that dyspnea assessment should include a measure of intensity and some inquiry into the associated bother or distress experienced by the patient. A simple question into the presence or absence of dyspnea would be unlikely to help guide therapy, as complete relief of dyspnea in advanced disease would not be anticipated.
	2010	A Framework for Assessing Quality Indicators for Cancer Care at the End-of-Life	The framework describes five steps for developing and assessing a quality indicator for end-of-life care, defining the (1) population of focus; (2) broad quality domains; (3) specific target areas; (4) steps of the care process; and (5) evaluation criteria for quality indicators. The defined population includes seriously or terminally ill cancer patients, who are unlikely to recover or stabilize, and their families. Domains include the structure and processes of care; physical, psychiatric, psychosocial, spiritual, and cultural aspects of care; as well as the care of the imminently dying, ethical legal issues, and the delivery of care. Evaluation criteria include importance; scientific acceptability, including validity, evidence to improve outcomes, reliability, responsiveness, and variability; usability; and feasibility, including ready data sources.
	2010	Cancer Quality-ASSIST Supportive Oncology Quality Indicator Set: Feasibility, Reliability, and Validity Testing	We successfully evaluated 78 indicators across the domains; results were similar in the two settings. We could not feasibly evaluate 3 indicators because of low prevalence; 22 indicators had significant interrater reliability issues, 9 had significant validity issues, and 3 had both reliability and validity issues, leaving a set of 41 indicators most promising for further testing and use in this population, with an overall kappa score of 0.85 for specified care.
Cochrane	2017	Early palliative care	This systematic review of a small number of trials indicates that early palliative care interventions may have

Collection		for adults with advanced cancer	more beneficial effects on quality of life and symptom intensity among patients with advanced cancer than among those given usual/standard cancer care alone. Although we found only small effect sizes, these may be clinically relevant at an advanced disease stage with limited prognosis, at which time further decline in quality of life is very common. At this point, effects on mortality and depression are uncertain. We have to interpret current results with caution owing to very low to low certainty of current evidence and between-study differences regarding participant populations, interventions, and methods. Additional research now under way will present a clearer picture of the effect and specific indication of early palliative care. Upcoming results from several ongoing studies (N = 20) and studies awaiting assessment (N = 10) may increase the certainty of study results and may lead to improved decision making. In perspective, early palliative care is a newly emerging field, and well-conducted studies are needed to explicitly describe the components of early palliative care and control treatments, after blinding of participants and outcome assessors, and to report on possible adverse events.
	2017	Psychosocial interventions for fatigue during cancer treatment with palliative intent	We found little evidence around the benefits of psychosocial interventions provided to reduce fatigue in adult patients with incurable cancer receiving cancer treatment with palliative intent. Additional studies with larger samples are required to assess whether psychosocial interventions are beneficial for addressing fatigue in patients with incurable cancer.
	2016	Palliative care interventions in advanced dementia	Very little high quality work has been completed exploring palliative care interventions in advanced dementia. There were only two included studies in this review, with variation in the interventions and in the settings that made it impossible to conduct a meta-analysis of data for any outcome. Thus, we conclude that there is insufficient evidence to assess the effect of palliative care interventions in advanced dementia. The fact that there are six ongoing studies at the time of this review indicates an increased interest in this area by researchers, which is welcome and needed.
	2015	Training and supportive programs for	The use of palliative care volunteers is likely to continue, but there is an absence of evidence to show how best to train or support them whilst maintaining standards of care for palliative care patients and their families.

	palliative care volunteers in community settings	
2015	Psychological therapies for sickle cell disease and pain	Evidence for the efficacy of psychological therapies in sickle cell disease is currently limited. This systematic review has clearly identified the need for well-designed, adequately-powered, multicentre randomised controlled trials assessing the effectiveness of specific interventions in sickle cell disease.
2013	Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers	The results provide clear and reliable evidence that home palliative care increases the chance of dying at home and reduces symptom burden in particular for patients with cancer, without impacting on caregiver grief. This justifies providing home palliative care for patients who wish to die at home. More work is needed to study cost-effectiveness especially for people with non-malignant conditions, assessing place of death and appropriate outcomes that are sensitive to change and valid in these populations, and to compare different models of home palliative care, in powered studies.
2012	Spiritual and religious interventions for well-being of adults in the terminal phase of disease	We found inconclusive evidence that interventions with spiritual or religious components for adults in the terminal phase of a disease may or may not enhance well-being. Such interventions are under-evaluated. All five studies identified were undertaken in the same country, and in the multi-disciplinary palliative care interventions it is unclear if all participants received support from a chaplain or a spiritual counsellor. Moreover, it is unclear in all the studies whether the participants in the comparative groups received spiritual or religious support, or both, as part of routine care or from elsewhere. The paucity of quality research indicates a need for more rigorous studies.
2011	Interventions for improving palliative care for older people living in nursing care homes	We found few studies, and all were in the USA. Although the results are potentially promising, high quality trials of palliative care service delivery interventions which assess outcomes for residents are needed, particularly outside the USA. These should focus on measuring standard outcomes, assessing cost-effectiveness, and reducing bias.

	2011	Non-invasive interventions for improving well-being and quality of life in patients with lung cancer	Nurse follow-up programmes and interventions to manage breathlessness may produce beneficial effects. Counselling may help patients cope more effectively with emotional symptoms, but the evidence is not conclusive. Other psychotherapeutic, psychosocial and educational interventions can play some role in improving patients' quality of life. Exercise programmes and nutritional interventions have not shown relevant and lasting improvements of quality of life. Reflexology may have some beneficial effects in the short term.
	2009	Multidisciplinary care for adults with amyotrophic lateral sclerosis or motor neuron disease	In the absence of randomised controlled trials or controlled clinical trials, the 'best' evidence to date is based on three ‘low’ and two ‘very low quality’ observational studies. These suggest 'very low quality evidence' for an advantage for mental health domains (only) of quality of life without increasing healthcare costs, and 'low level quality' evidence for reduced hospitalisation for MDC in low-intensity outpatient settings; and 'very low quality' evidence for improved disability in high-intensity settings. The evidence for survival is conflicting. These conclusions are tentative and the gap in current research should not be interpreted as proof that MDC is ineffective. Further research is needed into appropriate study designs; outcome measurement; caregiver needs; and the evaluation of optimal settings, type, intensity or frequency and cost-effectiveness of MDC in the MND population. Future research should focus on observational designs to assess care and outcomes in 'real-life' settings. The interface between neurology, rehabilitation and palliative care should be explored to provide long-term support for MND.
Health Technology Assessment Program	None		
Centers for Disease Control and Prevention	Nothing specific, 2016 Opioid Prescribing Guidelines for Chronic Pain		

Institute for Clinical and Economic Review	2016	Palliative Care in the Outpatient Setting	Overall, the evidence describing outpatient palliative care's benefit is stronger for QoL, resource utilization outcomes, patient satisfaction, and mood outcomes, with more limited evidence suggesting benefits on survival, symptom burden, psychosocial, and caregiver outcomes. These observations are consistent with the fact that outpatient palliative care programs are designed to increase patient social support, patient self-advocacy, and coordinated medical care; while palliative care is not focused on improved survival as an indicator of effectiveness, the survival benefit may be mediated by the other more directly influenced outcomes of interest (e.g., mood, QoL).
Veterans Administration Evidence-based Synthesis Program	2017	Integrated Outpatient Palliative Care in Oncology	With the increase in availability of clinical palliative care services, organizations have tested and implemented varying degrees and types of integration with oncology care. These can be evaluated using common instruments, like the Integrated Practice Assessment Tool based on the health care integration framework by Heath et al. Adapted from this framework, levels of integration across palliative care and oncology have recently been proposed in the Collaborative Care Continuum framework by Kaufmann et al. In addition to levels of integration, leaders have described various methods of integration of services, including co-rounding models for hospitalized patients, embedded or co-located outpatient clinical services, and standalone clinics or services. Further, organizations have had positive experiences with integrated services limited to particular disease or conditions, types of therapy (eg, investigational agents or novel immunotherapy drugs), or by embedding palliative care experts into non-patient-facing case discussions such as multidisciplinary oncology team meetings ("tumor boards"). In addition to other types of integration, much focus has been on the outpatient setting, which is where the majority of cancer care is delivered. For palliative care, the outpatient realm has been considered the "next frontier" of community-based palliative care services, and although growth is robust, many communities do not have access to non-hospital services.

National Consensus Project for Quality Palliative Care *National Coalition for Hospice and Palliative Care*	2018	Clinical Practice Guidelines for Quality Palliative Care, 4th edition	The NCP Guidelines, 4th edition, are organized into 8 domains: Domain 1: Structure and Processes of Care The composition of an interdisciplinary team is outlined, including the professional qualifications, education, training, and support needed to deliver optimal patient- and family-centered care. Domain 1 also defines the elements of the palliative care assessment and care plan, as well as systems and processes specific to palliative care. Domain 2: Physical Aspects of Care The palliative care assessment, care planning, and treatment of physical symptoms are described, emphasizing patient- and family-directed holistic care. Domain 3: Psychological and Psychiatric Aspects The domain focuses on the processes for systematically assessing and addressing the psychological and psychiatric aspects of care in the context of serious illness. Domain 4: Social Aspects of Care Domain 4 outlines the palliative care approach to assessing and addressing patient and family social support needs. Domain 5: Spiritual, Religious, and Existential Aspects of Care The spiritual, religious, and existential aspects of care are described, including the importance of screening for unmet needs. Domain 6: Cultural Aspects of Care The domain outlines the ways in which culture influences both palliative care delivery and the experience of that care by the patient and family, from the time of diagnosis through death and bereavement. Domain 7: Care of the Patient Nearing the End of Life This domain focuses on the symptoms and situations that are common in the final days and weeks of life. Domain 8: Ethical and Legal Aspects of Care Content includes advance care planning, surrogate decision-making, regulatory and legal considerations, and related palliative care issues, focusing on ethical imperatives and processes to support patient autonomy.

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