



Effective Health Care Palliative Care and Hospice Information for Cancer Patients and Families

Results of Topic Selection Process & Next Steps

The nominator is interested in a new evidence review on providing information about palliative care and hospice to cancer patients and families.

Because limited original research addresses the nomination, a new review is not feasible at this time. No further activity on this nomination will be undertaken by the Effective Health Care (EHC) Program.

Topic Brief

Topic Name: Palliative Care and Hospice information for Cancer Patients and Families

Nomination Date: 2/7/2018

Topic Brief Date: 8/10/2018

Authors

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Conflict of Interest: None of the investigators have any affiliations or financial involvement that conflicts with the material presented in this report

Background

- According to the National Cancer Institute palliative care is care given to improve the quality of life of people with a serious or life-threatening disease. The goal is to prevent or treat as early as possible the symptoms of a disease, side effects caused by treatment, and psychological, social, and spiritual problems related to a disease or its treatment. Also called comfort care, supportive care, and symptom management.¹
- Palliative care can be provided at any time from diagnosis to end of life, and the individual can continue to receive cancer treatment.¹
- Hospice is a part of an integrated palliative approach to care, focusing on care in the last weeks of life and discontinued attempts to cure or control disease.²
- Hospice may be confused with being on the hospice benefit, with specific criteria under Medicare. These criteria include
 - Certification that one is terminally ill with less than 6 month life expectancy
 - A signed statement choosing hospice care instead of routine Medicare-benefits
 - Receive care from a Medicare-approved hospice program.
- Providing early palliative care can improve patient outcomes.³

- Overall survival in those with terminal cancer was not found to be different between those with active treatment targeted at the underlying disease as compared to those in palliative care; and there was greater toxicity from treatment in those receiving active treatment.⁴
- Early use of palliative care has been endorsed in clinical practice guidelines, including those by American College of Chest Physicians⁵ and the American Society of Clinical Oncology⁶.
- Despite this, many patients do not receive palliative care.
- Palliative care is negatively associated with a system of diminished care which is seen as a 'lesser' treatment alternative, diminished possibilities for hope and achievement of goals previously centered upon cure and diminished choices for the circumstances of one's care given all other options have expired.⁷
- Barriers to palliative care include²
 - Limited resources to refer to
 - Limited awareness of available resources
 - Ignorance about palliative care
 - Reluctance to refer
 - Reluctance of the patient and/or family for referral
 - Restrictive palliative care program eligibility criteria

Nominator and Stakeholder Engagement: The nominator was consulted on the key questions and scope, and to provide additional information about the intended use of the proposed systematic review. They clarified that the scope should include providers as targets, and that communication tools rather than decision tools were most relevant.

The key question for this nomination is:

KQ 1. Does education about palliative care and/or hospice to patients and their families increase the use of palliative care or hospice and improve outcomes for people with lung cancer and their families?

KQ 2. Does education about palliative care and/or hospice to clinicians increase the use of palliative care or hospice and improve outcomes for people with lung cancer and their families?

To define the inclusion criteria for the key questions we specify the population, interventions, comparators, and outcomes (PICO) of interest (Table 1).

Table 1. Key Question and PICO

	KQ 1	KQ 2
Population	Individuals with cancer and their families	Clinicians caring for individuals with cancer
Intervention	Education about palliative care and/or hospice	Education about palliative care and/or hospice
Comparator	Usual care	Usual care
Outcomes	Utilization of palliative care, quality of life, symptom burden, health service utilization (ICU, hospitalization, ED visit, use of intensive/aggressive care), continued active cancer treatment	Utilization of palliative care, quality of life, symptom burden, health service utilization (ICU, hospitalization, ED visit, use of intensive/aggressive care), continued active cancer treatment

Abbreviations: ED=emergency department; ICU=intensive care unit; KQ=key question;

Methods

We assessed nomination for priority for a systematic review or other AHRQ EHC report with a hierarchical process using established selection criteria (Appendix A). Assessment of each criteria determined the need for evaluation of the next one.

1. Determine the *appropriateness* of the nominated topic for inclusion in the EHC program.
2. Establish the overall *importance* of a potential topic as representing a health or healthcare issue in the United States.
3. Determine the *desirability of new evidence review* by examining whether a new systematic review or other AHRQ product would be duplicative.
4. Assess the *potential impact* a new systematic review or other AHRQ product.
5. Assess whether the *current state of the evidence* allows for a systematic review or other AHRQ product (feasibility).
6. Determine the *potential value* of a new systematic review or other AHRQ product.

Appropriateness and Importance

We assessed the nomination for appropriateness and importance.

Desirability of New Review/Duplication

We searched for high-quality, completed or in-process evidence reviews published in the last three years on the key questions of the nomination. See Appendix B for sources searched.

Impact of a New Evidence Review

The impact of a new evidence review was qualitatively assessed by analyzing the current standard of care, the existence of potential knowledge gaps, and practice variation. We considered whether it was possible for this review to influence the current state of practice through various dissemination pathways (practice recommendation, clinical guidelines, etc.).

Feasibility of New Evidence Review

We conducted a literature search in PubMed (7/2013-7/2018); PsycINFO (8/2013-8/2013); and CINAHL (8/2013-8/2018). We reviewed all identified titles and abstracts for inclusion and classified them by study design, to assess the size and scope of a potential evidence review. See Appendix C for search strategies and links to the ClinicalTrials.gov search.

Compilation of Findings

We constructed a table with the selection criteria and our assessments (Appendix A).

Results

Appropriateness and Importance

This is an appropriate and important topic. See Appendix A.

Desirability of New Review/Duplication

A new evidence review on would be partly duplicative of an existing product. We identified two systematic reviews relevant to KQ 1 and 2; and one related to KQ 2. In addition we found two in-process reviews related to KQ 1, and one related to KQ 2. Collectively these reviews did not cover the scope of interventions of interest to the nominators: some reviews focused on a broader patient population, including non-cancer populations; and the completed SRs were not

specific enough to address the nomination questions. See Appendix A and Table 2, Duplication column.

Impact of a New Evidence Review

A new systematic review may have moderate impact. It is uncertain how best to overcome the barriers to the use of palliative care and hospice.

Feasibility of a New Evidence Review

A new evidence review is not feasible. We identified four studies relevant to KQ 1 and two studies relevant to KQ 2. See Table 2, Feasibility column.

Table 2. Key question and Results for Duplication and Feasibility

Key Question	Duplication (6/2015-6/2018)	Feasibility (8/2013-8/2018)
KQ 1: education for patients and families	Total number of identified systematic reviews: 4 <ul style="list-style-type: none"> • Other group: 2^{8,9} • In-process: 2^{10,11} 	<u>Size/scope of review</u> Relevant Studies Identified: 4 <ul style="list-style-type: none"> • Pre/post: 2^{12,13} • RCT: 1^{14,15} <u>Clinicaltrials.gov</u> <ul style="list-style-type: none"> • Recruiting: 1 • Not yet recruiting: 2
KQ 2: education for providers	Total number of identified systematic reviews: 2 <ul style="list-style-type: none"> • Other group: 1⁹ • In-process: 1¹⁶ 	<u>Size/scope of review</u> Relevant Studies Identified: 2 <ul style="list-style-type: none"> • Pre/post: 1^{17,18} <u>Clinicaltrials.gov</u> <ul style="list-style-type: none"> • Recruiting: 1

Abbreviations: AHRQ=Agency for Healthcare Research and Quality; KQ=Key Question;

Summary of Findings

- Appropriateness and importance: The topic is both appropriate and important.
- Duplication: A new review would not be duplicative of an existing product. We identified three completed SR and three in-process SR. However they do not address the diversity of outcomes and potential interventions of interest to the nominator.
- Impact: A new systematic review has moderate potential.
- Feasibility: A new review is not feasible. The evidence base is likely limited.

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Appendix A. Selection Criteria Summary

Selection Criteria	Assessment
1. Appropriateness	
1a. Does the nomination represent a health care drug, intervention, device, technology, or health care system/setting available (or soon to be available) in the U.S.?	Yes
1b. Is the nomination a request for a systematic review?	Yes
1c. Is the focus on effectiveness or comparative effectiveness?	Yes
1d. Is the nomination focus supported by a logic model or biologic plausibility? Is it consistent or coherent with what is known about the topic?	Yes
2. Importance	
2a. Represents a significant disease burden; large proportion of the population	It is estimated that 1.7 million new cases of cancer will be diagnosed in the US in 2018. ¹⁹ According to the WHO it is estimated that 14% of those needing palliative care receive it before dying. ²⁰
2b. Is of high public interest; affects health care decision making, outcomes, or costs for a large proportion of the US population or for a vulnerable population	Yes. Early palliative care appears to improve outcomes for patients with advanced cancer but relatively few access this type of care.
2c. Represents important uncertainty for decision makers	Yes. It is not clear how to best address patient and family barriers to use of palliative care and end-of-life care.
2d. Incorporates issues around both clinical benefits and potential clinical harms	Yes.
2e. Represents high costs due to common use, high unit costs, or high associated costs to consumers, to patients, to health care systems, or to payers	Yes

Selection Criteria	Assessment
3. Desirability of a New Evidence Review/Duplication	
3. Would not be redundant (i.e., the proposed topic is not already covered by available or soon-to-be available high-quality systematic review by AHRQ or others)	<p>Collectively the completed and in-process systematic reviews do not cover the scope of the nomination.</p> <p>We identified two systematic reviews that addresses a portion of KQ 1 and 2:</p> <ul style="list-style-type: none"> • Kirolos et al.⁸ This SR examined interventions to increase hospice referral and enrollment. • Oczkowski et al. This SR examined communication tools aimed at patients and providers around end-of-life issues.⁹ <p>These are not considered duplicative because they are not specific enough for the KQ of the nominator and they include a broad population, including non-cancer patients.</p> <p>We identified in-process reviews that may be relevant to KQ 1:</p> <ul style="list-style-type: none"> • Uneno et al.¹⁰ Barriers and facilitators for integration of palliative care with oncology care: a systematic review. <ul style="list-style-type: none"> ○ Correspondence with the lead author confirms that patient-targeted interventions such as patient education (studied in Project EMPOWER¹³) will be included in the review. ○ The review is expected to be completed later this year. • Abedini et al.¹¹ What are current interventions to reduce aggressive end of life care in cancer patients? <ul style="list-style-type: none"> ○ Correspondence with the investigators confirms that they have included patient/family communication as an intervention for reducing aggressive end of life care in cancer patients. ○ The review is expected to be completed in October 2018. <p>We found one in-process review relevant to KQ 2:</p> <ul style="list-style-type: none"> • Halkett et al.¹⁶ Online communication skills training for cancer and palliative care health professionals. <ul style="list-style-type: none"> ○ Correspondence with investigators clarified that studies will only be included if its intervention is online education for cancer health professionals on communication skills. Outcomes will include patient and family outcomes, health professional measures, and any post training measure. Investigators will exclude studies of patient education and studies which have health professional education which is not online. ○ A draft of the review will be available in December 2018. <p>Reviews related to KQ 2 that the nominator may find useful</p> <ul style="list-style-type: none"> • Kelley et al.²¹ A systematic review of continuing education interventions to prepare primary care providers in their patients' palliative and end-of-life care or MAiD (Medical Assistance in Dying). <ul style="list-style-type: none"> ○ This review does not look at the outcomes of interest to the nominator, but does assess provider related outcomes.
4. Impact of a New Evidence Review	

Selection Criteria	Assessment
4a. Is the standard of care unclear (guidelines not available or guidelines inconsistent, indicating an information gap that may be addressed by a new evidence review)?	It is unclear how best to overcome the barriers around lack of awareness and understanding about palliative care and hospice in patients and clinicians.
4b. Is there practice variation (guideline inconsistent with current practice, indicating a potential implementation gap and not best addressed by a new evidence review)?	Guidelines recommend early integration of palliative care with oncology care as a way to increase early utilization of palliative care.
5. Primary Research	
<p>5. Effectively utilizes existing research and knowledge by considering:</p> <ul style="list-style-type: none"> - Adequacy (type and volume) of research for conducting a systematic review - Newly available evidence (particularly for updates or new technologies) 	<p>We identified four¹²⁻¹⁵ studies relevant to KQ 1 and two^{17, 18} studies relevant to KQ 2. Due to the limited number of studies and diversity of interventions, a new systematic review is not feasible.</p> <p>For KQ 1</p> <ul style="list-style-type: none"> • Interventions included: <ul style="list-style-type: none"> • Web-based delivery of information about palliative care • Education about palliative care from a patient navigator • Psycho-educational intervention about palliative care and self-management • Outcomes included quality of life, symptom burden, knowledge about palliative care, and healthcare utilization <p>For KQ 2</p> <ul style="list-style-type: none"> • Intervention was provider education • Outcomes included healthcare utilization and referral to end-of-life providers. <p>ClinicalTrials.gov.</p> <p>KQ 1:</p> <ul style="list-style-type: none"> • Health Care Coach Support in Reducing Acute Care Use and Cost in Patients With Cancer-recruiting. NCT03154190 • EL CENTRO: Engaging Latinos in the Center of Cancer Treatment Options-not yet recruiting. NCT03602885 • Uncertainty in Illness in Palliative Care: an Intervention for Family Caregivers-not yet recruiting. NCT03518970 <p>KQ 2:</p> <ul style="list-style-type: none"> • PALLiON - PALLiative Care In ONcology (PALLiON)-recruiting. NCT03088202

Abbreviations: AHRQ=Agency for Healthcare Research and Quality; KQ=Key Question

Appendix B. Search for Evidence Reviews (Duplication)

Listed are the sources searched.

Search date: June 2015 to June 2018
AHRQ: Evidence reports and technology assessments, USPSTF recommendations
VA Products: PBM, and HSR&D (ESP) publications, and VA/DoD EBCPG Program
Cochrane Systematic Reviews and Protocols http://www.cochranelibrary.com/
PubMed
PubMed Health http://www.ncbi.nlm.nih.gov/pubmedhealth/
PROSPERO Database (international prospective register of systematic reviews and protocols) http://www.crd.york.ac.uk/prospéro/
Systematic Reviews (Journal) : protocols and reviews http://systematicreviewsjournal.biomedcentral.com/

Abbreviations: AHRQ=Agency for Healthcare Research and Quality; DoD=Department of Defense; EBCPG=Evidence-based Clinical Practice Guideline; ESP=Evidence Synthesis Program; HSR&D=health Services Research and Development; PBM=Pharmacy Benefits Management Services; USPSTF=United States Preventive Services Task Force; VA=Veterans Administration

Appendix C. Search Strategy & Results (Feasibility)

Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R) 1946 to August 13, 2018

Date Searched: August 14, 2018

Searched by: Robin Paynter, MLIS

#	Searches	Results
1	exp Neoplasms/ or (blastoma* or cancer* or carcinoma* or fibroadenoma* or hemangioma* or leukemia* or leukaemia* or lymphoma* or malignan* or melanoma* or meningioma* or metastat* or myeloma* or neoplas* or nodule* or neurofibroma* or oncolog* or sarcoma* or teratoma* or tumor* or tumour*).ti,ab,kf.	4036625
2	Palliative Care/ or Palliative Medicine/ or Hospice Care/ or "Hospice and Palliative Care Nursing"/ or Hospices/ or Terminal Care/ or (palliative or hospice* or "end of life" or "terminal care").ti,kf.	82453
3	and/1-2	37180
4	Patient Education as Topic/ or Patient Education Handout/ or Advance Directives/ or Communication/ or Clinical Decision-making/ or Decision Making/ or Directive Counseling/ or Consumer Health Information/ or Counseling/ or ("advance care planning" or "advance directive*" or counsel* or decision* or education* or directive* or goal* or "support care").ti,ab,kf.	1290828
5	3 and 4	5792
6	limit 5 to english language	5231
7	limit 6 to (adaptive clinical trial or clinical trial, all or controlled clinical trial or pragmatic clinical trial or randomized controlled trial)	400
8	limit 6 to (meta analysis or systematic reviews)	306

PsycINFO 1806 to August Week 1 2018

Date Searched: August 16, 2018

Searched by: Robin Paynter, MLIS

#		
1	exp Neoplasms/ or Terminal Cancer/ or Terminally Ill Patients/ or Oncology/ or (blastoma* or cancer* or carcinoma* or fibroadenoma* or hemangioma* or leukemia* or leukaemia* or lymphoma* or malignan* or melanoma* or meningioma* or metastat* or myeloma* or neoplas* or nodule* or neurofibroma* or oncolog* or sarcoma* or teratoma* or tumor* or tumour*).ti,ab,id.	82439
2	Palliative Care/ or Hospice/ or (palliative or hospice* or "end of life" or "terminal care").ti,ab,id. or "3375".cc.	29811
3	and/1-2	7750
4	Client Education/ or Disease Management/ or Decision Support Systems/ or Health Knowledge/ or Advance Directives/ or Communication/ or Decision Making/ or Counseling/ or Information/ or Psychoeducation/ or Client Attitudes/ or Attitude Formation/ or Professional Consultation/ or ("advance care planning" or "advance directive*" or counsel* or decision* or education* or directive* or goal* or handout* or "support care").ti,ab,id.	893636
5	3 and 4	2687
6	limit 5 to english language	2593
7	limit 6 to "0300 clinical trial"	33
8	limit 6 to ("0830 systematic review" or 1200 meta analysis or 1300 metasyntesis)	61

CINAHL Plus with Full Text

Date Searched: August 17, 2018

Searched by: Robin Paynter, MLIS

#	Search Options	LIMITS	RESULTS
S5	S1 AND S2 AND S3	English Language; Exclude MEDLINE records; Publication Type: Meta Analysis, Review, Systematic Review	73
S4	S1 AND S2 AND S3	English Language; Exclude MEDLINE records; Publication Type: Clinical Trial, Randomized Controlled Trial	14

#	Search Options	LIMITS	RESULTS
S3	(MH "Patient Education") OR (MH "Communication") OR (MH "Health Personnel Education") OR (MH "Death Education") OR (MH "Education") OR (MH "Health Education") OR TI (attitud* OR consult* OR counsel* OR decision* OR education* OR directive* OR goal* OR handout*) OR AB (attitud* OR consult* OR counsel* OR decision* OR education* OR directive* OR goal* OR handout*)		621,009
S2	(MH "Hospice Care") OR (MH "Hospice and Palliative Nurses Association") OR (MH "Palliative Care") OR (MH "Hospice and Palliative Nursing") OR TI (palliative OR hospice*) OR AB (palliative OR hospice*)		48,139
S1	(MH "Cancer Patients") OR TI ((blastoma* OR cancer* OR carcinoma* OR fibroadenoma* OR hemangioma* OR leukemia* OR leukaemia* OR lymphoma* OR malignan* OR melanoma* OR meningioma* OR metastat* OR myeloma* OR neoplas* OR nodule* OR neurofibroma* OR oncolog* OR sarcoma* OR teratoma* OR tumor* OR tumour*) N3 patient*) OR AB ((blastoma* OR cancer* OR carcinoma* OR fibroadenoma* OR hemangioma* OR leukemia* OR leukaemia* OR lymphoma* OR malignan* OR melanoma* OR meningioma* OR metastat* OR myeloma* ...		127,581

Clinicaltrials.gov

https://clinicaltrials.gov/ct2/results?term=palliative&cond=cancer&recrs=b&recrs=a&recrs=f&recrs=d&age_v=&age=1&gndr=&type=&rslt=&Search=Apply

<https://clinicaltrials.gov/ct2/results?cond=cancer&term=education&cntry=&state=&city=&dist=&Search=Search&recrs=a&recrs=b&recrs=d&recrs=f&age=1&age=2>

<https://clinicaltrials.gov/ct2/results?term=palliative+care+education&cond=Cancer&age=12>

<https://clinicaltrials.gov/ct2/results?cond=Cancer&term=provider+education&cntry=&state=&city=&dist=&Search=Search&age=1&age=2>