



8. Improving Health Care and Palliative Care for Advanced and Serious Illness

**Closing the Quality Gap:
Revisiting the State of the
Science**



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Practice**

8. Improving Health Care and Palliative Care for Advanced and Serious Illness

Closing the Quality Gap: Revisiting the State of the Science

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions, and new health care technologies and strategies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

In 2004, AHRQ launched a collection of evidence reports, *Closing the Quality Gap: A Critical Analysis of Quality Improvement Strategies*, to bring data to bear on quality improvement opportunities. These reports summarized the evidence on quality improvement strategies related to chronic conditions, practice areas, and cross-cutting priorities.

This evidence report is part of a new series, *Closing the Quality Gap: Revisiting the State of the Science*. This series broadens the scope of settings, interventions, and clinical conditions, while continuing the focus on improving the quality of health care through critical assessment of relevant evidence. Targeting multiple audiences and uses, this series assembles evidence about strategies aimed at closing the “quality gap,” the difference between what is expected to work well for patients based on known evidence and what actually happens in day-to-day clinical practice across populations of patients. All readers of these reports may expect a deeper understanding of the nature and extent of selected high-priority quality gaps, as well as the systemic changes and scientific advances necessary to close them.

AHRQ expects that the EPC evidence reports will inform consumers, health plans, other purchasers, providers, and policymakers, as well as the health care system as a whole, by providing important information to help improve health care quality.

We welcome comments on this evidence report or the series as a whole. Comments may be sent by mail to the Task Order Officer named in this report to: Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850, or by email to epc@ahrq.hhs.gov.

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Improving Health Care and Palliative Care for Advanced and Serious Illness

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Structured Abstract

Objective. To systematically review the evidence on the effectiveness of health care and palliative care interventions to improve outcomes for patients with advanced and serious illness.

Data Sources. We searched MEDLINE®, CINAHL, PsycINFO, Cochrane, and DARE from 2000 through 2011. We identified additional studies from reference lists of eligible articles and relevant reviews, as well as from technical experts.

Review Methods. We developed questions in collaboration with technical experts. We excluded retrospective and uncontrolled studies. Two investigators independently screened search results and abstracted data from eligible studies. We adapted previous frameworks to categorize included studies (e.g., by improvement target, setting). Because many studies did not report effect sizes and almost all studies were small (<200 studies), in order to be able to quantitatively describe the literature, we calculated the percentage of studies with a significant improvement in outcomes with the intervention compared to control group for each category. We also checked that all other studies did not report significant results in the opposite direction and checked that there were not differences between larger and smaller studies.

Results. We included 90 studies described in 96 articles. Of the 23 studies targeting continuity, coordination, and transitions, 33 percent of studies that evaluated quality of life as an outcome, 67 percent that evaluated patient satisfaction, and 31 percent that evaluated health care utilization (admissions and length of stay) found a statistically significant improvement with the intervention. Of the 21 studies targeting pain, almost all focused on patient education and self-management; 48 percent of them found a statistically significant improvement with the intervention. Findings for larger (>100) and smaller (≤100) studies were similar. For distress, only 29 percent of the seven included studies found a statistically significant impact. Of the 20 studies in communication and decisionmaking, only 22 percent of studies addressing patient or family satisfaction found a statistically significant improvement for this outcome, compared to 73 percent for the outcome of health care utilization. We found only two studies within hospice programs, both of which found a statistically significant improvement in at least one outcome; nine studies were in nursing homes, 78 percent of which demonstrated a significant improvement with the intervention.

In terms of types of quality improvement, for the target of continuity, studies including patient-centered quality improvement types, such as education and self-management, had the strongest evidence of effectiveness on patient- and family-centered domains such as satisfaction and quality of life. Studies of provider-focused interventions (e.g., education, reminders) were more likely to have an impact on health care utilization. Only one of five studies addressing multiple targets and focusing on facilitated relay of clinical data to providers demonstrated a statistically significant improvement in either quality of life or satisfaction. In terms of consultative and integrative interventions, for the target of communication and decisionmaking, three-quarters of consultative interventions showed a statistically significant improvement with

the intervention, compared to half of integrative interventions. The literature was too heterogeneous and effect sizes were too infrequently reported for quantitative synthesis. There was moderate strength of evidence for the target of continuity, coordination, and transitions and the outcome of patient and caregiver satisfaction but low strength of evidence for other outcomes. For the target of pain, there was moderate strength of evidence for pain as an outcome. For the target of communication and decisionmaking, there was moderate strength of evidence for the outcome of health care utilization but low strength of evidence for other outcomes.

Conclusions. We found that evidence was strongest (moderate strength of evidence) for interventions for pain, and for the targets of communication and decisionmaking 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 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. Future research needs include techniques for improving recruitment and retention to assure adequate sample size, better development and description of interventions, and further development and standardization of outcome measures and tools.

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Executive Summary

Background

Although extensive evidence supports the effectiveness of clinical interventions for improving palliative care for patients with advanced and serious illness, many studies have found that these interventions are often not used sufficiently in practice.^{1,2} As part of a larger review of interventions aimed at reducing the quality gap (the difference between health care processes or outcomes observed in practice and evidence-based practices potentially obtainable on the basis of current professional knowledge), we conducted a review focusing on interventions to improve care and outcomes in patients with advanced and serious illness. We defined the included population as seriously ill patients and those with advanced disease (such as people living with advanced cancer or intensive care unit patients at high risk of dying) who are unlikely to be cured, recover, or stabilize.^{3,4} We classified interventions to improve care for this population by the framework shown in Figure A.⁵ The framework shows the literature in palliative care as a grid, with different populations, domains of care, targets of quality improvement, settings (and integrated care), conditions, and categories of relevant interventions. The targets show the areas where an intervention might focus—such as an intervention specifically targeting pain management in patients with advanced disease. Areas that were the focus of this review are underlined in the figure.

Objectives and Key Questions

The objective of this report was to evaluate the effectiveness of health care and palliative care interventions on patient-centered outcomes relevant to palliative care, including quality improvement interventions. For the purpose of this review, we focused on targets related to palliative care, including pain; communication and decisionmaking; continuity, coordination, and transitions of care; and patient and family distress (defined as an unpleasant emotional experience that can be psychological, social, and/or spiritual). We also focused specifically on interventions within hospice care and in the nursing home setting. We analyzed studies to address how different types of quality improvement interventions can improve these targets of care in terms of populations, settings, and outcomes.

The Key Questions for the report follow.

Key Question 1. What is the effectiveness of health care and palliative care interventions for improving the quality of palliative care?

- a. **Specific targets:** What is the effectiveness in terms of processes and outcomes for pain; communication and decisionmaking; continuity, coordination, and transitions of care; and patient and family distress in palliative care populations?
- b. **Specific settings:** What is the effectiveness of interventions for any target of palliative care within hospice programs or nursing homes?

Figure A. Analytic framework for interventions for advanced and serious illness systematic review

1. Population Definition-Advanced and Serious Illness	2. Domains of Interventions	3. Targets for Interventions	4. Settings	5. Types of Interventions
<p>National Consensus Project's definition of palliative care adapted:</p> <p>■ Seriously ill patients and those with advanced disease (such as persons living with advanced cancer or intensive care unit patients at high risk of dying), who are unlikely to be cured, recover, or stabilize, and their caregivers.</p> <p>Conditions: Cancer Heart failure End-stage lung disease Dementia Frailty</p>	<p>Structure</p> <p>Processes</p> <p>Physical</p> <p>Psychological & Psychiatric</p> <p>Social</p> <p>Spiritual, Religious, & Existential</p> <p>Cultural</p> <p>Care of Imminently Dying</p> <p>Ethical and Legal</p> <p>Other</p>	<p>Interdisciplinary teams Case management</p> <p>Interdisciplinary assessment</p> <p><u>Pain</u> Dyspnea Nausea Vomiting Fatigue</p> <p><u>Distress</u> Delirium Depression Psychosocial support for families</p> <p>Family Support/caregiving</p> <p>Value/meaning</p> <p>Cultural assessment</p> <p>Prognosis discussion/ documentation Comfort care</p> <p>Advance care planning</p> <p><u>Communication/Decisionmaking</u> <u>Continuity/Coordination/Transitions</u> Use of technology / Overutilization Staff distress, competence, retention Patient safety: Falls</p>	<p>Settings: <u>Hospice</u> <u>Nursing home</u> Outpatient (primary care, oncology) Inpatient Intensive care Integrated</p>	<p>Structural -Institutional/local policies</p> <p><u>Integrative</u>: embedding palliative care principles and interventions into daily practice - Provider education - Organizational strategies</p> <p><u>Consultative</u>: increasing the use and effectiveness of palliative care consultants/other nonintegrative interventions -Triggering criteria - Scope of consultation - Quality of consultation services</p> <p>Closing the Quality Gap categories of quality improvement, particularly: -<u>Patient-centered interventions</u> (education, self-management) -<u>Provider-centered interventions</u> (education, reminders) - <u>Facilitated relay of clinical data to providers</u></p>

Note: Areas that were the focus of this review are underlined.

Key Question 2: What is the evidence for different quality improvement models for improving palliative care?

- What is the evidence for different types of quality improvement interventions?
- What is the evidence for different models in palliative care: integrative compared with consultative?

We evaluated each target for whether Key Question 2a or 2b was more applicable, and only one of these questions was analyzed for each target. (They were mutually exclusive.)

“Health care and palliative care interventions” apply to interventions to improve care, including quality improvement interventions.

The intent of the Key Questions was to describe the evidence in each area (e.g., target, quality improvement type, setting), not to compare the different areas with each other.

“Targets” relate to the targets of the intervention, such as pain; communication and decisionmaking; continuity, coordination, and transitions; and patient and family distress, and not to outcomes. (See column 3 in Figure A.)

“Integrative” refers to interventions that embed palliative care principles and interventions into daily practice, and “consultative” refers to interventions that increase the use and effectiveness of palliative care consultants or other nonintegrative interventions (See column 5 in Figure A).⁶

Methods

Inclusion and Exclusion Criteria

We included studies on seriously ill patients and those with advanced disease who met the population definition given below, including studies on pediatric and geriatric populations. We also included studies with outcomes related to the families/caregivers of these patients. Patients with all conditions (e.g., cancer, heart failure, end-stage lung disease, dementia, and frailty) were included.

Since there are high-quality studies in this field, we excluded all retrospective and uncontrolled studies of interventions. We excluded individual studies published before 2000 because the nature of both quality improvement and palliative care practice has changed substantially since that time. Palliative care has grown markedly as a specialty and service since 2000, and the populations served by hospice care were also markedly different before 2000. In addition, the pre-2000 data have been thoroughly addressed in a previous Evidence-based Practice Center report⁷ and an extensive National Institute for Clinical Excellence (United Kingdom) report.^{8,9}

We included any timing of followup, including interviews after the patient's death with families/caregivers. We addressed all settings, both inpatient and outpatient, as well as interventions in inpatient or outpatient hospice or palliative care programs.

The detailed PICOTS (populations, interventions, comparators, outcomes, timing, and setting) eligibility criteria used for inclusion/exclusion of articles for Key Questions 1 and 2 in this topic area follow.

Population(s)

We defined the relevant population as “seriously ill patients and those with advanced disease (such as people living with advanced cancer or intensive care unit patients at high risk of dying), who are unlikely to be cured, recover, or stabilize” (adapted from the National Consensus Project³).

Interventions

We included studies evaluating health care and palliative care interventions, including quality improvement interventions, such as patient education and self-management, and provider audit and feedback.

Comparators

We included all comparators. For most studies, this was usual health care, but some studies tested interventions that were added to usual hospice or palliative care.

Outcome Measures for Each Key Question

For both Key Questions, we included all relevant patient or family/caregiver-centered outcomes, including:

- Patient and family satisfaction/perceptions of palliative care
- Patient symptoms, needs, distress, and quality of life

- Health care utilization, such as hospital admissions or do-not-resuscitate orders (but not costs)
- Quality-of-care measures, such as timeliness of response to pain and other symptoms
- Family/caregiver psychosocial symptoms, support, needs, quality of life, and grief/bereavement

We excluded studies that did not report measurements of any of these outcomes or that only had outcomes not related directly to the target populations (e.g., staff knowledge or perceptions of care).

Timing

We included any timing of followup, including interviews after the patient's death with families/caregivers.

Settings

We addressed all settings, both inpatient and outpatient, with a specific focus on the nursing home setting (primary) and hospice program setting (specialty), as underlined in the analytic framework. (See column 4 in Figure A.)

Input From Experts

We developed questions in consultation with a variety of technical experts from areas of research, clinical care, and policy.

Data Sources and Selection

We searched PubMed®, CINAHL, PsycINFO, Cochrane, and DARE from 2000 through 2011. We identified additional studies from reference lists of eligible articles and relevant reviews, as well as from technical experts. We limited our review to prospective intervention studies that included a control group.

Data Extraction and Quality Assessment

Each abstract was independently screened by two reviewers. These reviewers included a trained article screener and a content expert. Abstracts were promoted to be screened using the full-text article if both reviewers agreed that the abstract could apply to one or more of the Key Questions. An abstract could be excluded for different reasons by the two reviewers. Disagreements about the eligibility of an abstract were resolved by discussion between the two reviewers or by adjudication of a third reviewer.

Full-text articles underwent another independent review by paired investigators. If articles were deemed to have applicable information, they were included for data abstraction. Articles were promoted to data abstraction if both reviewers agreed. An article could be excluded for different reasons by the two reviewers. Disagreements about the eligibility of an article were resolved by discussion between the two reviewers or by adjudication of a third reviewer.

All screening was completed using the DistillerSR Web-based systematic review software (Evidence Partners, Ontario, Canada).

No forms were used for data abstraction in this systematic review. Due to the nature of the data (narrative), we used a consecutive two-reviewer process to abstract data from the included articles. In this process, a research assistant abstracted data directly to tables, and these data were checked by a senior investigator. Periodically, senior investigators cross-checked the work of the other senior investigators to ensure that abstractions were done appropriately. Reviewers were not masked to the articles' authors, institutions, or journal.¹⁰ Disagreements that could not be resolved between the reviewers were resolved through consensus adjudication at team meetings.

We used a tool implemented successfully in past Evidence-based Practice Center projects, including the Cochrane Collaboration Tool for Assessing Risk of Bias from the Cochrane Handbook for Systematic Reviews of Interventions for assessing randomized controlled trials.¹¹ Data abstraction forms were not developed for this phase of the review, and elements of the data abstraction can be found in the evidence tables.

We assessed the risk of bias and appropriateness of all studies that met our eligibility criteria, following the guidance contained in chapter 6 of the Agency for Healthcare Research and Quality's Methods Guide for Effectiveness and Comparative Effectiveness Reviews.¹⁰ We used a limited number of the key criteria that are most appropriate for each study design and that are most important for determining the validity of the studies. After the pool of included articles in this review was determined, the core team of investigators determined that the Cochrane Collaboration tool¹¹ was the tool most appropriate for all risk-of-bias assessments. Although we considered assessing risk of bias separately for nonrandomized studies, we were unable to identify any validated tools that worked well in this literature and could be compared with risk-of-bias tools designed for randomized trials. We did not factor in the quality score for blinding of the intervention; we did this because blinding of patients and personnel was generally not feasible in these interventions, although blinding of outcomes assessors would have been possible. A low risk of bias was assessed if six or more of the items were scored as a "yes." A medium risk of bias was assessed if four or five of the items were scored as a "yes" or "unclear." A high risk of bias was assessed if zero to three items were scored as a "yes."

Data Synthesis

We adapted previous frameworks⁵ to categorize included studies by target and setting of the intervention, including a category for interventions that focused on multiple targets or targets other than the primary ones for this review, and evaluated each target category for applicability to each Key Question. Each target category was evaluated for applicability to either Key Question 2a (types of quality interventions) or Key Question 2b (integrative compared with consultative model) and evaluated only for that part of Key Question 2. To determine whether results could be quantitatively synthesized, we evaluated the diversity of studies, measurement tools, and outcome reporting. Because effect sizes were often not reported, most studies were small (<200 patients), interventions and outcomes were diverse, and there was concern for selective outcome reporting, we judged that quantitative synthesis was not appropriate due to clinical and methodological diversity. Therefore, to be consistent with most previous systematic reviews in this literature, for each category, we calculated the percentage of studies with a statistically significant improvement in outcomes with the intervention compared to control. We also checked that all other studies did not report significant results in the opposite direction.

Grading

We assessed the strength of the best available evidence, including the risk of bias in relevant studies, as well as aspects of consistency, directness, and precision where applicable.¹² Based on these aspects, evidence for each outcome was graded as insufficient, low, moderate, or high.

Results

Results are summarized in Table A by target and outcome, and in the text below by Key Questions addressed for each target from Figure A. We included 90 studies described in 96 articles in the review (Figure B). We described the information abstracted in a systematic manner but did not conduct any meta-analyses. The interventions, outcomes, and outcome reporting were too diverse to allow for any synthesis.

Interventions Targeting Continuity, Coordination of Care, and Transitions

Key Question 1a. Evidence About Target

We found 23 studies described in 26 articles focusing on the targets of continuity, coordination of care, and/or transitions in care, including interventions such as palliative care consultation, case management, and hospice screening and referral. Twelve studies were randomized controlled trials (RCTs). The studies addressed a wide variety of populations, settings, and outcomes, with most studies evaluating multiple types of outcomes.

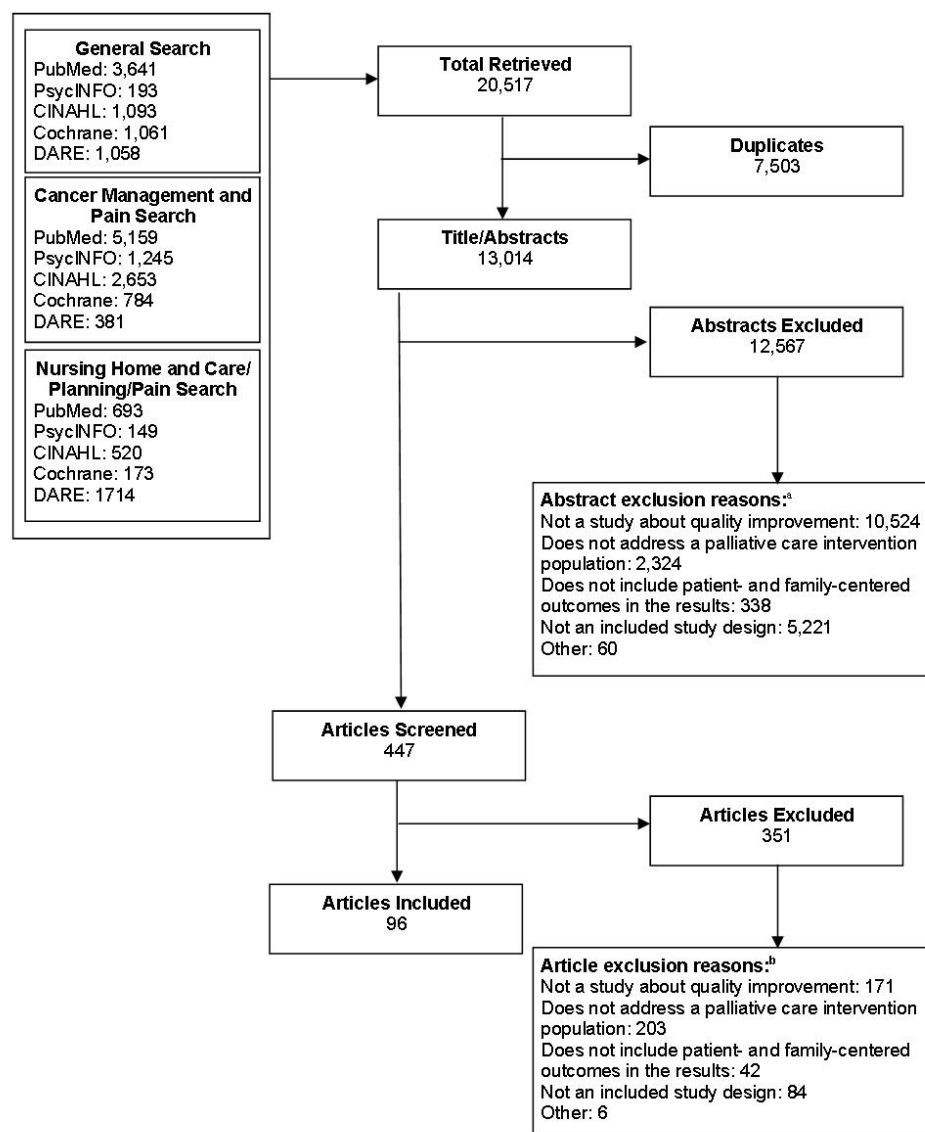
Of the nine studies that evaluated patient quality of life, only three (33 percent) showed a statistically significant improvement with the intervention compared with the control group. Of the six trials that evaluated patient satisfaction, four (67 percent) showed a statistically significant improvement with the intervention. Three of the five studies (60 percent) that evaluated family satisfaction showed a significant improvement. None of the eight studies that measured the effect on overall symptoms demonstrated a significant improvement with the intervention on this outcome. Only 5 of the 16 studies (31 percent) that evaluated health care utilization found a statistically significant improvement with the intervention on this outcome. Interventions and outcomes were too diverse for meta-analysis.

Strength of evidence was low for improvement in patient quality of life, symptoms, and health care utilization, and moderate for improvement in patient and family satisfaction.

Key Question 1b. Evidence About Settings

For hospice care, one RCT that examined systematic feedback from standardized assessments and interdisciplinary team discussions showed a statistically significant improvement with the intervention on one outcome. For nursing homes, one of three studies on care pathways showed a statistically significant improvement with the intervention, as did one study on screening for hospice eligibility.

Figure B. Results of the literature search



^a The sum of reasons for exclusion at abstract screening is greater than the total number of exclusions because each reviewer could select a different reason for exclusion.

^b The sum of reasons for exclusion at article screening is greater than the total number of exclusions because each reviewer could select a different reason for exclusion.

Table A. Summary of key data, by target, for all types of quality improvement interventions and settings

Target	Outcome	Strength of Evidence ^a That the Intervention Improved Outcomes Compared With the Control Group
Continuity, Coordination of Care, and Transitions (KQ1a and KQ2a)	Patient quality of life	Low
	Patient satisfaction	Moderate
	Caregiver burden	Low
	Caregiver satisfaction	Moderate
	Overall symptoms	Low
	Health care utilization	Low
Pain (KQ1a and KQ2a)	Pain	Moderate
	Quality of life	Low
Distress (KQ1a and KQ2a)	Distress	Low
	Depression	Low
Communication and Decisionmaking (KQ1a and KQ2b)	Patient satisfaction	Low
	Family satisfaction	Insufficient
	Health care utilization	Moderate
	Quality of life	Low
	Symptom control	Low
Multiple and Other Targets (KQ2a)	Quality of life	Low
	Satisfaction	Low
	Quality of care	Low
	Patient symptoms	Low
	Psychosocial support	Low

^aStrength of evidence is based mainly on the strength of the study designs (with randomized trials considered the strongest design) and on consistency based on the percentage of studies with a statistically significant improvement in the outcome, while checking that no studies had a significant worsening of the outcome. This approach was necessary because of inconsistent reporting of outcomes across studies and frequent lack of reporting of effect size or confidence intervals.

Note: KQ = Key Question. KQ2a or KQ2b was analyzed for each target as more appropriate; they were mutually exclusive. Table does not address KQ1b; some targets did not have any hospice or nursing home studies, and none had more than a few—insufficient for strength of evidence by target. There were insufficient numbers of studies to compare different quality improvement types or quality improvement models within any of the targets.

Key Question 2a. Evidence About Types of Quality Improvement

For the outcomes of quality of life and satisfaction, studies using patient-centered quality improvement types, such as patient/family/caregiver education and promotion of self-management, showed a significant improvement in satisfaction and quality of life in six of nine studies. Of six studies that included provider-centered quality improvement interventions (provider reminder systems, facilitated relay of clinical data to providers, or provider education) but did not include patient-centered quality improvement interventions, none demonstrated effectiveness on quality of life or satisfaction. For the outcome of health care utilization, such as admissions or length of stay, only 5 of the 16 studies (31 percent) reported a statistically significant improvement with the intervention compared to the control group.

Key Question 2b. Evidence About Integrative and Consultative Models

This Key Question was not analyzed for this target.

Interventions Targeting Pain

Key Question 1a. Evidence About Target

We found 21 studies addressing the target of pain in patients with advanced and serious illness; 19 were in cancer populations. Sixteen studies were in the ambulatory setting, and 18 were RCTs. Fourteen studies used the Brief Pain Inventory as the pain measurement tool.

Ten of the studies (48 percent) found that the interventions had a statistically significant effect on improving pain scores. Similar findings were noted when including only larger studies (100-200 patients); 5 of these 11 studies (45 percent) had significant findings. The interventions and outcome measurement and reporting were too diverse, and reporting of effect sizes was too inconsistent, for quantitative synthesis, and there was concern about selective outcome reporting. Eight of the studies also measured quality of life as an outcome; only one of those studies found any effect of the intervention on quality of life, and this study found improvement on only a single subscale. Strength of evidence was moderate for improvement in pain and low for improvement in quality of life.

Key Question 1b. Evidence About Settings

Two RCTs targeted pain in nursing homes using pain screening interventions for end-stage dementia. Both found a statistically significant improvement with the intervention.

Key Question 2a. Evidence About Types of Quality Improvement

Three studies used provider-level interventions only, and 18 employed patient and/or family caregiver education and self-management. Half of the studies employing patient and/or family caregiver education and self-management used print or video material to enhance the intervention. Four of the six studies that used an educational video followed by printed materials to enhance the educational intervention showed statistically significant improvement in pain scores, compared with one of the three studies that used either print material alone or video material alone.

Key Question 2b. Evidence About Integrative and Consultative Models

This Key Question was not analyzed for this target.

Interventions Targeting Distress

Key Question 1a. Evidence About Target

We found seven studies of interventions that targeted patient distress in patients with advanced and serious illness. All seven studies were RCTs. Four of these studies were based in ambulatory settings, and six were in cancer populations. Only two of the seven studies (29 percent) demonstrated a significant improvement in distress with the intervention compared to the control group. One study examined detailed distress screening combined with personalized telephone triage for referral to resources, and a second study looked at telephone-based coping skills training in lung transplant candidates. Interventions and outcomes were too diverse for meta-analysis. Strength of evidence was low for improvement in distress and depression.

Key Question 1b. Evidence About Settings

There were no studies in hospice or nursing homes for this target.

Key Question 2a. Evidence About Types of Quality Improvement

Six of the seven studies focused on patient education and self-management as a quality improvement method; only one of these six studies found a statistically significant improvement with the intervention.

Key Question 2b. Evidence About Integrative and Consultative Models

This Key Question was not analyzed for this target.

Interventions Targeting Communication and Decisionmaking

Key Question 1a. Evidence About Target

We found 20 studies of interventions targeting communication and decisionmaking with patients with advanced and serious illness. Nine were RCTs, 13 were conducted in an intensive care unit, and most were in mixed-illness populations. Interventions included family meetings with the usual health care team (11 studies), interdisciplinary palliative care teams (4 studies), ethics consultations (2 studies), and physician-patient communication (2 studies). Only one of eight studies that evaluated patient satisfaction showed a statistically significant improvement with the intervention on this outcome, and one of three studies that evaluated family satisfaction showed a significant impact. On the other hand, of 15 studies that evaluated health care utilization as an outcome, 11 (73 percent) showed a statistically significant improvement with the intervention. Interventions and outcomes were too diverse for meta-analysis. Strength of evidence was low for improvement in satisfaction and moderate for improvement in health care utilization.

Key Question 1b. Evidence About Settings

No studies addressed hospice. One study, measuring end-of-life outcomes in nursing homes, found that educating providers, patients, and families about advance directives improved health care utilization, but there was no impact on satisfaction.

Key Question 2a. Evidence About Types of Quality Improvement

This Key Question was not analyzed for this target.

Key Question 2b. Evidence About Integrative and Consultative Models

Eight interventions were integrative, and four of the eight (50 percent) showed a statistically significant improvement with the intervention. Eight interventions were consultative, and six of the eight (75 percent) found a statistically significant improvement with the intervention. Only four studies combined integrative and consultative models.

Interventions Targeting Multiple and Other Targets

Key Question 1a. Evidence About Target

This Key Question was not analyzed for multiple and other targets.

Key Question 1b. Evidence About Settings

For the hospice setting, one study on training caregivers in symptom management techniques found a statistically significant improvement with the intervention. For the nursing home setting, one study of a provider education intervention showed a statistically significant improvement with the intervention, as did one study including multiple quality improvement types.

Key Question 2a. Evidence About Types of Quality Improvement

For facilitated relay of clinical data to providers, we found six publications on five studies. All were RCTs in cancer patients. The interventions involved health-related quality of life surveys with feedback to physicians. Only one of the five studies demonstrated that the intervention had a significant effect on quality of life or satisfaction. Of two studies of audit and feedback, a multicenter study found significant improvements, but a single-center study found no impact on measures of quality of care. The one study focusing on provider education in nursing homes found the intervention had a statistically significant improvement on measures of quality of care.

For patient/caregiver education and self-management, we found six publications on five studies that addressed multiple targets and symptoms or quality of life. Four of the five studies found statistically significant improvement with the intervention. We found one study focusing on organizational change (a before-after study of a rapid-response clinic for palliative radiotherapy), which found a statistically significant improvement in the use of single-fraction treatment (guideline-recommended care) and a reduction in time to treatment. We did not identify any studies for provider reminder systems or for financial incentives, regulation, and policy.

We identified three studies that focused on multiple quality improvement types and multiple targets. One study was an RCT based on an initial non-RCT. This RCT (in intensive care units) found no significant impact on any outcomes. Another study in the nursing home setting found a statistically significant improvement for multiple outcomes.

Finally, we found two studies that did not fit any of the quality improvement types. Both evaluated new clinical services in palliative care. One found no significant impact of a palliative daycare intervention and the second, an RCT of hospital services provided in the home setting for palliative care, found a statistically significant improvement with the intervention on only one of multiple outcomes measured. Interventions and outcomes were too diverse for meta-analysis, and strength of evidence was low for improvement in outcomes.

Key Question 2b. Evidence About Integrative and Consultative Models

This Key Question was not analyzed for multiple and other targets.

Discussion

Brief Review of Main Findings

Among the types of interventions evaluated in this report, for the target of continuity, coordination, and transitions, we found moderate strength of evidence for improvement in satisfaction but low strength of evidence for improvement in quality of life and health care utilization. In contrast, we found moderate strength of evidence for the target of communication and decisionmaking for improvement in the outcome of health care utilization but not for

improvement in satisfaction; three-quarters of the interventions that evaluated utilization (mostly in the intensive care unit setting) found a statistically significant impact on health care utilization outcomes. Moderate strength of evidence was found for patient-centered pain interventions for improvement in the outcome of pain, and strength of evidence was low for improvement in distress. For studies addressing multiple targets, only one of five studies of facilitated relay of clinical data to providers found a statistically significant improvement with the intervention. In reference to the question of integrative compared with consultative interventions, for the target of communication and decisionmaking, three-quarters of consultative interventions showed a statistically significant improvement with the intervention, compared to half of integrative interventions. Seven of the nine interventions to improve care in the nursing home setting showed an improvement in at least one outcome. Although the quality of studies overall was mixed, we noted the presence of selected high- and medium-quality, well-designed studies for most of the target areas and Key Questions.

Description of Clinical Context and Applicability of Evidence for Decisionmaking

Several high- and medium-quality, well-designed, multicenter interventions to improve health care for patients with advanced and serious illness with consistent results across outcomes now exist. However, this report highlights the continued presence of variable findings, study quality deficiencies, ill-defined interventions, and insufficient use of appropriate measurement tools for the intervention and for patients with advanced and serious illness in much of the literature.

For policymakers, this report underscores the continuing strong need for research funding for well-designed studies to evaluate quality improvement and policy interventions, particularly in areas that are advancing rapidly in health care policy (e.g., feedback and financial and regulatory interventions) but have not been rigorously evaluated.

Summary of Weaknesses or Gaps of the Evidence and Description of Limitations of the Review

As with all systematic reviews, our results and conclusions depend on the quality of the published literature. Due to clinical and methodological diversity in outcomes, populations, interventions, and measurement tools; concerns about selective outcome reporting; and lack of reporting of effect sizes or confidence intervals in most studies, we judged that qualitative description of the literature was more appropriate than quantitative synthesis. The quality of many studies was moderate to low. Common quality issues included small sample sizes, often due to insufficient recruitment and high rates of attrition, and issues with outcome measures not designed for advanced or serious illness or not well coordinated with the purpose of the intervention. Descriptions of interventions were often limited, difficult to interpret, and challenging to categorize into the quality improvement types. Few studies reported information on disparities, context, or theory or logic models.

Implications for Future Research

We identified several key areas for future research. The field of palliative care has clearly advanced significantly since the 2004 evidence report on end-of-life care and outcomes.⁸ The quality of research in this field could be improved by recruitment and retention efforts to assure

adequate sample size, better development and description of interventions, inclusion of theory and quality improvement techniques, consideration of context, matching and pilot testing of outcomes for interventions, standardization of outcome measures across interventions, and clearer and consistent reporting of outcomes. Development of measurement instruments specific to this population has advanced, but more development is needed for measuring certain domains and to better understand how to match outcome measures to interventions. We identified few studies in hospice populations and no studies focusing on reducing disparities in outcomes. In both these areas, there is significant need, and there are significant challenges in developing and evaluating quality improvement interventions. Finally, the use of different quality improvement types was limited in studies focusing on populations with serious and advanced illness, particularly for the targets of pain and distress.

Conclusions

In conclusion, we found the most consistent evidence in a large number of studies, including several high- and medium-quality studies, for the effectiveness of interventions targeting continuity for improvement in the outcome of patient satisfaction, targeting pain using patient-centered interventions, and targeting communication and decisionmaking for impacting health care utilization outcomes in the intensive care unit setting. The evidence has multiple gaps, including studies in illnesses other than cancer for symptom management; in pediatric populations and hospice settings; and addressing diverse populations and disparities in care. More coordinated initiatives across multiple settings and providers, and following patient populations over longer periods of time, will be needed to better understand how best to improve care and outcomes for patients with advanced and serious illness.

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Introduction

Background and Context

Extensive evidence supports the effectiveness of clinical interventions for improving patient-centered outcomes for patients with advanced and serious illness. For example, many types of medications and other interventions to treat pain,¹ can lead to significant reductions in pain severity and pain-related outcomes such as quality of life.² However, studies in different areas have found that these are often not well integrated into medical practice. For pain, despite widely accepted pain screening and clinical practice guidelines,³ pain continues to be undertreated, particularly for vulnerable populations such as nursing home patients.⁴ For communication and decisionmaking, in a study of audiotaped initial oncology consultations for patients with terminal cancer, fewer than half of oncologists offered alternatives to chemotherapy as an option. In addition, only 58 percent of patients were informed of their life expectancy and only 60 percent were aware of uncertainty about the benefits of chemotherapy.⁵ And despite wide availability and insurance coverage of hospice care, in 2009, only 42 percent of patients who died in the United States received any hospice care, and, of those, only half received more than three weeks of care.⁶

This report is part of a larger review of interventions aimed at reducing the quality gap (the difference between health care processes or outcomes observed in practice and evidence-based practices potentially obtainable on the basis of current professional knowledge).⁷ Given the critical importance of interventions to improve health care and palliative care in this population, we focused on these types of interventions in this report. These interventions can include changes in the way care is provided within a system, such as palliative care consultation services, and interventions to change how patients/families interact with the health care system, such as a patient self-management program for pain that is integrated with patients' health care. They can also include quality improvement interventions, (quality improvement; see Appendix A for a list of acronyms) which can be defined as any type of intervention to improve care with some element of system change, including change in how patients/families interact with the health care system, and can be delivered through a variety of quality improvement methods, such as continuous quality improvement. The common purpose of these types of interventions is to improve care and self-management to maximize the quality of life of people facing advanced and serious illnesses and the end of life and of their families. This includes relief from physical and psychosocial symptoms; psychosocial and spiritual support for both the patient and their families and other caregivers; excellent communication about topics such as prognosis; person-centered care, with compassion, personalization, and cultural sensitivity; care planning and prevention of crises; and opportunities for comfortable dying, life closure, and control of the circumstances of death.

For the purposes of this review, we address the needs of patients with advanced and serious illnesses through the three interrelated areas of palliative care, end-of-life care, and hospice care. Palliative care is defined as medical care focused on improving the quality of life of people facing serious or life-threatening illness, including the end of life. It is often provided as a service or quality improvement intervention, and can be delivered in any setting. Emphasis is placed on pain and symptom management, communication, and coordinated care. End-of-life care is defined as care delivered to dying patients, and is a small subset of palliative care. Hospice is also a subset of palliative care and is defined as a care delivery system and insurance benefit for patients in the last months of life who have chosen quality of life as the primary goal of care, and

which is provided, in the United States, wherever the patient resides. In the United States, these include the home, special inpatient units, and nursing homes.

We focused on several specific targets that are critical to improving care in this population: continuity, coordination of care, and transitions; pain; distress; and communication and decisionmaking. The next sections define these targets and health care and palliative care interventions that might improve them, and summarize evidence from previous systematic reviews for the targets and settings that are the focus of this review.

Continuity, Coordination of Care, and Transitions

Continuity can be defined as the exchange of knowledge and the relationships between providers and patients/families, or between providers and/or provider groups. Continuity includes three areas: relational continuity, focusing on the relationship between patients/families and providers; management continuity, focusing on the relationship between providers (e.g., developing interdisciplinary teams); and informational continuity, focused on improving information exchange (e.g., improving patient assessment in palliative care domains). Coordination of care is a challenge for many patients with serious illness, including aligning care across settings; communicating with physicians; and incorporating multiple complex treatments for the patient. Improving transitions includes both improving the process of transitions that occur, and facilitating the initiation of appropriate transitions, such as enrollment in hospice care. Specialized palliative care services usually involve an interdisciplinary team, usually a physician and a nurse, social worker, pharmacist, and/or chaplain. Services focus on continuity and coordination of care, including assisting with transitions to hospice, and also include communication, decisionmaking support, and care planning, symptom management, and psychosocial, spiritual, and bereavement support. Because of these services' focus on continuity and coordination, and for consistency with an earlier systematic review,⁸ we classified these services in the target of continuity.

Several previous systematic reviews have addressed the target of continuity in palliative care, although one review addressed populations with serious illness much more broadly, and the other two focused solely on specialized palliative care interventions, and none of the reviews addressed broader quality improvement interventions in this target or the role of quality improvement within palliative care interventions. A review through 2006 on evidence for improving palliative care, addressing broader populations with chronic illness,⁸ defined continuity as addressing relationships with providers over time. The review found that studies in congestive heart failure, dementia, and nursing homes (many focusing on case management and transitions), generally did not focus on end-of-life populations or issues. The review also found two previous systematic reviews on this topic in end-of-life care. One review of case management in end-of-life care identified four RCTs, with two that evaluated utilization, having mixed effects. A review of improved coordination for supportive cancer care identified nine RCTs of portable records (mostly negative studies) or palliative care–home care coordination (with mixed effects for patient and caregiver outcomes and utilization). The review identified one additional study specific to end-of-life care, which found that palliative case managers increased advance directives and lowered utilization.

Several systematic reviews have addressed the effectiveness of specialized palliative care both generally,⁸⁻¹² and in AIDS¹³ and cancer^{14,15} populations. The most recent review addressing all populations¹¹ focused on RCTs of specialized palliative care (trained professionals) published through 2007. Outcomes included quality of life, satisfaction, or costs; half were in the home

setting, and half focused on cancer patients; 12 of the studies evaluated a multidisciplinary team. The review found the strongest evidence for effectiveness in the area of satisfaction (seven out of the 10 studies evaluated that outcome found a significant impact of the intervention), compared to four out of the 13 studies that evaluated quality of life outcomes (although almost all of these studies were underpowered) and only one out of seven studies evaluating the outcome of cost.

The most recent review on specialized palliative care in cancer¹⁴ focused on similar outcomes, and concluded that there was evidence for effectiveness for palliative care in both the home and hospital setting, mainly for the outcomes of pain and symptom management, hospital admissions, and satisfaction. Some improvements were also noted in anxiety and depression and caregiver quality of life. This review also found less evidence for effectiveness in patient quality of life.

Pain

Pain is one of the most common symptoms in individuals with cancer that is directly associated with significantly reduced quality of life.^{16,17} Poorly-managed cancer pain is an important quality of care outcome and a high priority for patients, clinicians, and health care policy. A recent systematic review estimated that among individuals with metastatic cancer, an average of 64 percent of patients experienced pain.¹⁸ Cancer pain is most commonly the result of tumor load,¹⁹ but is also frequently associated with treatments, such as surgery or chemotherapy. Because pain is implicated with disease progression, frequent reassessment and changes in management are required to ensure quality of life and care.²⁰ Yet, despite the importance of pain ascertainment and management, under-treatment is common,²¹ affecting as many as 40 percent of patients.²²

Quality improvement strategies to improve pain management in patients with advanced and serious illness include patient and caregiver education, provider education, systematic pain assessment, and use of clinical decision tools to improve appropriate prescribing of analgesia. Several prior systematic reviews addressing the impact of quality improvement interventions for pain in patients in various stages of cancer, have demonstrated mixed findings. A 2001 review of pain management interventions found evidence that quality improvement interventions focused on providers improved provider knowledge and attitudes, but did not have significant positive impact on patient pain ratings.²³ While provider-focused interventions were not found to be effective in this review, nurse-led patient directed educational interventions were found to have a positive effect on patient pain levels. Moreover, systematic pain assessment was found to have some promise in improving patient pain outcomes. A 2009 systematic review and meta-analysis of patient-based educational interventions²⁴ included 21 trials (19 RCTs), 15 of which were included in a meta-analysis which found that interventions successfully reduced both average and worst pain intensity.

A systematic review focusing on studies of hospitalized cancer patients²⁵ found five studies addressing education, audit and feedback, decision support, and pain consultation. Some evidence was found for the impact of interventions on satisfaction and quality of care, but not for pain outcomes. A 2007 review²⁶ found effective studies in the domains of institutionalization models (e.g., routine pain assessment), clinical pathways, and pain consultation. A 2011 review of knowledge translation interventions targeted at improving cancer pain through either health care providers or patients and family caregivers found that, generally, knowledge translation had a positive impact on pain outcomes. Better outcomes were observed with higher frequency and intensity of educational programs.²⁷ These reviews all addressed pain in broad populations with

cancer or hospitalized patients, and did not focus on patients with advanced disease or serious illness, who have different types of pain management needs and may require different quality improvement approaches.

Distress

Distress can be defined as a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with illness, its physical symptoms and its treatment.²⁸ The term is broader than specific psychiatric diagnoses such as depression, and can apply to the psychosocial and emotional impact of illness on both patients and caregivers/families. Recommended interventions to include distress include screening in the cancer care setting, psychosocial interventions such as social work consultation and counseling, and spiritual counseling.

Several systematic reviews have addressed psychosocial interventions for family caregivers in palliative care²⁹ and in adult³⁰ and adolescent³¹ cancer patients, as well as psychotherapy for depression in incurable cancer patients.³² Although these reviews did find some evidence for the effectiveness of these types of interventions, they generally did not focus on distress as an outcome or end-stage illnesses, and did not address the issue of quality improvement for this target.

Communication and Decisionmaking

Effective communication and decisionmaking between providers, and between providers and patients and families, constitutes the foundation for the tasks of palliative care. Thus, the quality of communication for patients with advanced and serious illness is a key determinant of patient and family outcomes. Key aspects of communication and decisionmaking with this population include: sharing information about diagnosis, prognosis and goals of care; engaging families in treatment decisionmaking; and offering psychosocial support. Interventions include increasing the frequency of communication about these issues (such as regularly scheduled family meetings), and increasing the quality of communication (such as implementing structured templates).

Several previous systematic reviews have focused on quality improvement in communication in relevant areas. Lorenz et al,⁹ in a 2008 systematic review, found moderate evidence supporting effectiveness of interventions to increase advance directive rates, although little evidence on patient outcomes. The review also identified studies supporting the effectiveness of a variety of communication interventions. In a 2008 review, Walling et al.³³ found similar results, and also found that broader end-of-life communication interventions had demonstrated effectiveness for patient satisfaction and psychological outcomes. Finally, a 2011 review of studies focusing on communication in the intensive care setting³⁴ found evidence supporting the effectiveness of regular, structured communication and palliative care and ethics consultations for the outcomes of distress and health care utilization.

Settings of Care

End-of-life care occurs across all settings, and interventions identified in previous systematic reviews have focused mainly on the hospital and home setting, with some interventions in the outpatient, hospice, and nursing home setting. Quality improvement is important in hospices,

which are specifically focused on end-of-life care, because variation in quality also exists within hospice programs. In the Family Evaluation of Hospice Care from the National Hospice and Palliative Care Organization,³⁵ (completed, in a general hospice population including patients with cancer and other illnesses, by families after hospice patients' deaths), 18.2 percent of family members noted problems with attention to family needs for support (variation among hospices, 25th and 75th percentiles, 12.6 and 21.4 percent), and 9.8 percent of family members reported unmet need for emotional support (variation among hospices, 25th and 75th percentiles, 5.4 and 13.3 percent).³⁶ No previous systematic reviews focused on quality improvement in the hospice setting. Because of this, and because of the importance of hospice care in end-of-life care and current quality improvement initiatives, we focused specifically on this setting as part of our review.

Approximately 20 percent of deaths in the United States occur in nursing homes or shortly after transfer from a nursing home to a hospital.³⁷ Evidence on palliative care in nursing homes has demonstrated major deficits in palliative care processes such as advance care planning, pain management, and psychosocial support. Two systematic reviews have focused on quality improvement in nursing homes, but did not focus on end-of-life populations. One of these reviews, targeting pain management,³⁸ identified a variety of quality improvement studies using provider education, decision support, and systems changes, but found few high-quality studies and high reliance on process rather than patient outcomes. Because of the lack of previous reviews focusing on end-of-life care in the nursing home setting, and because of the importance of this setting to end-of-life care, we also focused on this setting in our review.

Scope

Current approaches to providing palliative care or improving quality in key patient-centered targets in advanced and serious illness (e.g., the targets of communication and pain) vary widely, and there is clear need for information on what types of interventions can improve palliative care for patients. Although there have been a number of systematic reviews related to this topic, recent reviews have focused mainly on palliative care and hospice interventions and on specific domains, settings, or populations (e.g., communication, intensive care unit, cancer), and none have used the perspective of quality improvement. There are some studies of different types of interventions (case management, ordersets, and improvement of communication), but they are not specifically addressed in these reviews, and key reviews of pain interventions in cancer and nursing homes have not focused on patients with advanced illness.

With regard to hospice, in spite of the huge range of quality improvement interventions (case management, provider and patient education, targeted patient interventions, structured ordersets, and patient screening for eligibility for palliative care services or specific needs), little systematic information is available on which types of interventions work for hospice. This lack of evidence is especially notable since providers are now required by the Center for Medicare and Medicaid Services to have a quality assurance program with a quality improvement component.

Framework for the Systematic Review

The framework (Figure 1) is derived from the National Quality Forum palliative care framework and a recent consensus project conducted to develop a framework for end-of-life cancer quality measurement.^{39,40} The framework shows the literature in end-of-life care as a grid, with different populations, domains of care, targets of quality improvement, settings (and integrated care), and categories of quality improvement relevant to palliative care.

The targets show the areas where an intervention might focus—such as an intervention specifically targeting pain management in patients with advanced disease. To apply the framework for prioritizing areas for the review, we conducted an initial environmental scan of systematic reviews, consulted with experts, and considered needs of key stakeholders and audiences for the review, to determine domains and settings where this review would be most valuable. Underlined areas show where we prioritized the searches and review, but all areas in the framework were included. For the first Key Question, we included targets where there was a substantial literature but not covered in recent reviews, and two settings of particular interest to key audiences and not covered in recent reviews. In the second Key Question, we focus on types and models of quality improvement, applying them to studies both in specific target areas and to studies addressing multiple targets. We designed the scope in this way to focus on key areas in end-of-life care that had not been addressed in previous reviews and to make the results of our review focused enough to draw clear conclusions.

Key Questions

Key Question 1. What is the effectiveness of health care and palliative care interventions for improving the quality of palliative care?

- a. Specific targets: What is the effectiveness in terms of processes and outcomes for pain; communication and decisionmaking; continuity, coordination, and transitions; and patient and family distress; in palliative care populations? (See Figure 1, Framework for end-of-life and hospice care, column 3, for a listing of targets of quality improvement.)
- b. Specific settings: What is the effectiveness for interventions for any target of palliative care within hospice programs or nursing homes?

Key Question 2: What is the evidence for different quality improvement models for improving palliative care?

- a. What is the evidence for different types of quality improvement interventions? (See the Interventions section below and framework, column 5 of Figure 1.)
- b. What is the evidence for different models in palliative care: integrative, compared with consultative? (See column 5 of Figure 1, framework, for definitions.)

We evaluated each target for whether Key Question 2a or 2b was most applicable, and only one of these questions was analyzed for each target (they were mutually exclusive).

The intent of the Key Questions was to describe the evidence in each area (e.g., target, quality improvement type, setting), not to compare the different areas to each other.

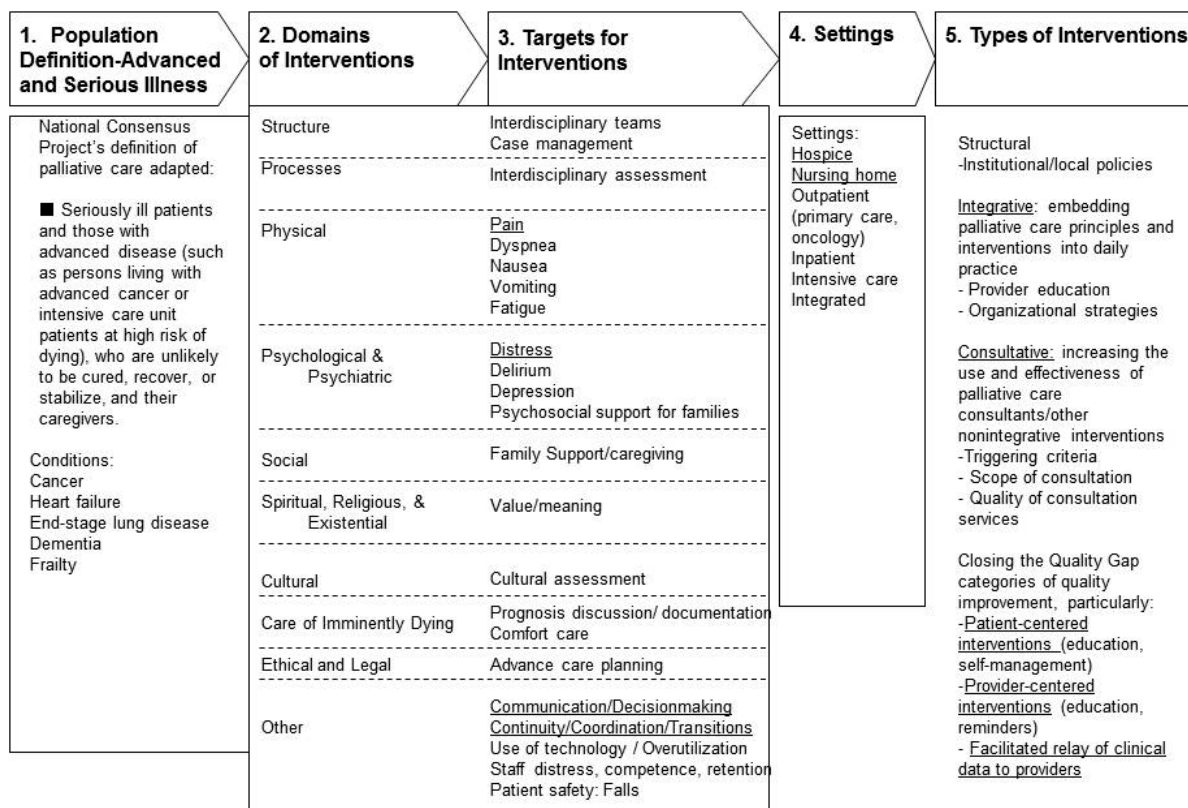
“Targets” relate to the targets of the intervention, e.g. pain; communication and decisionmaking; continuity, coordination, and transitions; and patient and family distress, and not outcomes (see column 3 in the framework).

“Integrative” refers to interventions that embed palliative care principles and interventions into daily practice, and “consultative” refers to interventions that increase the use and effectiveness of palliative care consultants or other non-integrative interventions (see column 5 in the framework)

Uses of This Report

Audiences who might find value from the report include professionals in both palliative care and hospice programs, as well as those in other settings with a significant percentage of patients with serious and advanced disease, such as cancer centers, medicine inpatient units, and nursing homes. Other potential audiences include health care professionals (e.g., physicians, nurses, social workers, and pharmacists) and relevant health care professional organizations (e.g., Academy of Hospice and Palliative Medicine, Hospice and Palliative Nurses Association), for quality initiatives and education; key funders in this area (e.g., National Cancer Institute, National Institute on Aging, National Institute of Nursing Research); and staff of organizations investing in palliative care quality improvement and systems initiatives (e.g., Center for Medicare and Medicaid Services, Veterans Health Administration, Kaiser, Institute for Healthcare Improvement), as well as organizations representing hospice and palliative care programs (e.g., the National Hospice and Palliative Care Organization). Researchers in palliative care and relevant fields, as well as relevant policymakers (e.g., The National Quality Forum's National Priorities Partnership³⁹) and members and staff of advocacy groups (e.g., American Cancer Society) will also be able to use the contents of the review. This report may be useful to help researchers plan areas to target and intervention types and outcome measures to use; and for health care organizations' decisionmaking on what types of programs to implement.

Figure 1. Analytic framework for interventions for advanced and serious illness systematic review



Methods

Overview

Advanced and Serious Illness

For the purposes of this review, we defined the relevant population as “seriously ill patients and those with advanced disease (such as people living with advanced cancer or intensive care unit patients at high risk of dying), who are unlikely to be cured, recover, or stabilize.” We adapted this definition from the National Consensus Project⁴¹ definition of palliative care, which covers a broader population, to keep the scope of the review relatively focused on patients with advanced and serious illness. We covered the entire lifespan, including populations from pediatrics to geriatrics. We also included outcomes related to families and caregivers of these patients (e.g., depressive symptoms of family members of intensive care unit (ICU) patients). We included patients with all conditions meeting the population definition (e.g., critically ill patients and those with heart failure, end-stage lung disease, dementia, and advanced or metastatic cancer).

Many studies included diverse populations (e.g., cancer survivors, patients with early-stage disease, and patients with advanced disease). In these situations, we included studies where more than 50 percent of the included population would fit the above definition, or where results were reported separately for the advanced disease population. Where results were reported separately, we included the results only for the relevant portion of the population. For studies where the “seriously ill” portion of the definition of end-of-life care was most relevant (e.g., ICU populations), we included studies where the expected one-year mortality of the included population would be at least 50 percent.

Interventions To Improve Care and Quality Improvement

In determining how to define and categorize health care and palliative care interventions to improve care in this field, including quality improvement, we considered several ways that care for patients with advanced and serious illness may differ from care in prevention or chronic illness. Palliative care is a diverse field that often addresses complex and diverse diseases using a multidisciplinary approach. This type of care can have many different types of targets and outcomes, and can therefore involve many different types of interventions. Palliative care interventions can include palliative care consultation or case management programs; ordersets addressing multiple targets or programs targeting transitions between settings; and interventions targeting nonmedical aspects of care, such as psychosocial stresses or caregiver burden. These types of palliative care interventions will likely require different types of quality improvement, as well as different targets, and outcomes, than would be needed in more medical, unidimensional illnesses (such as asthma or hypertension). In addition, a key informant study of palliative care and hospice providers⁴² identified potential external barriers to quality improvement, such as the lack of resources and models for quality improvement, lack of evidence for best practices, and concerns that traditional models of quality improvement may not work well for hospice. Finally, improvement efforts in this area often involve interventions such as counseling for psychosocial and/or spiritual distress, which are more challenging to discern from quality improvement because of the inclusion of interpersonal interactions than, for example, administration of a medication.

We reviewed definitions from systematic reviews of quality improvement, (Table 1) including the Closing the Quality Gap series,^{7,43} as well as the reviews themselves to better understand how the definition was applied to different clinical areas like care coordination, asthma, and hypertension. We reviewed resources developed by the Cochrane Effective Practice and Organization of Care Group (<http://epoc.cochrane.org/>), which focuses on systematic reviews of interventions designed to improve the delivery, practice, and organization of health care services. We examined another review on quality improvement studies that evaluated the reliability of a definition for identifying quality improvement interventions, and a review on quality improvement theory.^{43,44} Because psychological distress and support were targets of our review, we also contacted experts and searched for definitions of quality improvement in mental health care used in reviews of mental health quality improvement interventions, but did not locate any that were relevant. We used these definitions to develop a clear definition for quality improvement in patients with advanced and serious illness that met the needs of this review.

Table 1. Quality improvement definitions relevant to palliative care

Definition of Quality Improvement	Systematic Review
Interventions aimed at reducing the quality gap (the difference between health care processes or outcomes observed in practice and those potentially obtainable on the basis of current professional knowledge) for a group of patients representative of those encountered in routine practice. The intervention targeted implementation of a particular process of care (or set of processes) believed to benefit patients with the priority condition(s); i.e., interventions designed to improve provider adherence to a clinical best practice guideline, or those intended to increase the proportion of patients who received recommended care. The intervention targeted implementation of a structural or organizational feature believed to benefit patients with the priority condition; i.e., interventions that changed the care provider, added supplemental personnel, or made clinical information systems part of the treatment protocol.	CQG, 2004 ⁴³
Studies were identified as relevant to quality improvement for the CQG if any one of the following applied: 1. The intervention was designed to increase the proportion of patients receiving recommended processes of care (i.e, those demonstrated to improve outcomes for patients with the condition of interest), including aspects of diagnosis and screening, therapeutic interventions, and patient education or counseling. 2. The intervention implemented organizational or structural features likely to benefit patients with the condition of interest.	CQG, 2004 ⁴³
An effort to change/improve the clinical structure, process, and/or outcomes of care by means of an organizational or structural change Definition for effectiveness, impacts, or success: Effectiveness: The comparative effectiveness of the intervention relative to an alternative intervention or usual care Impacts: The degree to which the intervention results in changes over time in relevant outcomes for the patients and organizations involved Success: The degree to which the intervention achieves its goals relative to 1) achieving benchmarks or targets for clinical care, acceptability, adoption, implementation, spread, or sustainability/maintenance, and 2) the logic model for the intervention	Danz, 2010 ⁴⁵
Quality improvement theory was defined as a set of principles that involve knowledge, skills, and methods used to evaluate and implement change in a health care system using a systems-based approach.	Boonyasai, 2007 ⁴⁶

Abbreviation: CQG= Closing the Quality Gap

Based on this review, we developed the following definition of quality improvement as applied to patients with advanced or serious illness and palliative care:

Interventions targeting improvement for patients with advanced or serious illness that are conducted within or linked with the health care system and that have at least some element of

system change, or intended change in how the patient/family/caregiver would interact with the system, and address one of the palliative care targets.

Taxonomy of Quality Improvement

We based our categories on the taxonomy from the Closing the Quality Gap Series,⁴³ but adapted them slightly to meet the literature in this area, and added one category on provider training/support on quality improvement skills, as well as a category for “other” for any interventions that did not fit these categories. Interventions could include multiple types of quality improvement interventions (Table 2).

A consensus report published by the Improving Palliative Care in the ICU group in September 2010 noted that there are “two main models for ICU-palliative care integration: (1) the ‘consultative model,’ which focuses on increasing the involvement and effectiveness of palliative care consultants in the care of ICU patients and their families... and (2) the ‘integrative model,’ which seeks to embed palliative care principles and interventions into daily practice by the ICU team for all patients and families facing critical illness.”⁴⁷ The consensus report listed multiple examples of consultative versus integrative palliative care initiatives for ICU patients, but noted that it is unclear which “structure of a palliative care initiative... can best meet the needs of ICU patients, their loved ones, clinicians, and the hospital.” A complete systematic review of these initiatives with initiative classification as primarily “integrative” or “consultative” could determine which model is more efficacious, and would be applicable to most settings outside the ICU as well where palliative and other medical services could work together. From a comparative effectiveness perspective, understanding in what circumstances each model is best supported by the evidence can help practitioners choose which model to adopt in particular situations.

Topic Refinement and Review Protocol

Topics for the Closing the Quality Gap series were solicited from the portfolio leads at AHRQ. The nominations included a brief background and context; the importance and/or rationale for the topic; the focus or population of interest; relevant outcomes; and references to recent or ongoing work. Among the topics that were nominated, the following considerations were made in selection for inclusion in the series: the ability to focus and clarify the topic area appropriately; relevance to quality improvement and a systems approach; applicability to the Evidence-based Practice Center program/amenable to systematic review; the potential for duplication and/or overlap with other known or ongoing work; relevance and potential impact in improving care; and fit of the topics as a whole in reflecting the AHRQ portfolios.

Table 2. Types of quality improvement in hospice and palliative care (adapted from CQG⁴³)

Physician/other provider reminder systems (such as prompts in paper charts or computer-based reminders) (would include comfort care or other ordersets, structured communication templates for providers)
Facilitated relay of clinical data to providers (patient data transmitted by telephone call or fax, from outpatient specialty clinics to primary care physicians) (would include structured documentation tools, collection of patient-reported outcomes)
Audit and feedback (physician performance tracking and reviews, using quality indicators and reports, comparisons with national/State quality report cards, publicly released performance data, and benchmark outcomes data).
Physician/other provider education (workshops and professional conferences, educational outreach visits, distribution of educational materials).
Provider training/support on quality improvement skills
Patient education (classes, parent and family education, pamphlets and other media, etc.).
Promotion of self-management (workshops, materials such as structured prompt sheets for patients to ask physicians about palliative care issues).
Patient reminder systems (telephone calls or postcards from physicians to their patients).
Organizational changes (PDSA, collaboratives, multidisciplinary teams, shifting from paper-based to computer-based recordkeeping, long-distance case discussion between professional peers).
Financial incentives, regulation, and policy (performance-based bonuses and alternative reimbursement systems for physicians, positive or negative financial incentives for patients, and changes in professional licensure requirements) (would include state policy, POLST or similar programs, advance directive policy)
Other types of interventions

Abbreviations: CQG=Closing the Quality Gap; POLST= Physicians Orders for Life Sustaining Treatment

Literature Search Strategy

Comprehensive search strategies were developed through an analysis of studies known to be eligible for this review and related systematic reviews. These strategies combined controlled vocabulary terms (e.g., MeSH, EMTREE terms) with free-text terms (Appendix B, Detailed Search Strategies).

In order to ensure that the search was comprehensive without capturing articles that did not apply to certain targets, separate searches were developed to capture studies on: (1) palliative care/patients with advanced and serious illness and quality improvement (Appendix Table B.1); (2) cancer/cancer care and communication/distress/pain management (Appendix Table B.2); and (3) nursing homes and care planning/pain management (Appendix Table B.3). Each of the search strategies was developed using PubMed and comparable searches were developed using the following databases: CINAHL, PsycINFO, Cochrane, and DARE (Appendix Tables B.1–B.3). We reviewed reference lists of included articles for potentially relevant studies. We also identified systematic reviews that might contain relevant articles and reviewed these reference lists as well. Searches were updated through December 31, 2011, and were downloaded to the ProCite[®] reference database.

Gray Literature

We sought supplemental publications from our technical expert panel, including requests for any “gray literature” sources, and reviewed these publications as well as their references for potentially eligible articles. We did not conduct any additional gray literature searches, since another systematic review in palliative care found that addition of the gray literature did not affect the results.⁴⁸

Inclusion and Exclusion Criteria

We included studies on seriously ill patients and those with advanced disease that met the population definition, including studies on pediatric and geriatric populations. We also included

studies with outcomes related to the families/caregivers of these patients. Patients with all conditions (e.g., cancer, heart failure, end-stage lung disease, dementia, and frailty) were included.

Since there are high-quality studies in this field, we excluded all retrospective and uncontrolled studies of quality improvement interventions. We excluded individual studies published before 2000 because the nature of both quality improvement and palliative care practice has changed substantially since that time; and the populations served by hospice care were also markedly different before 2000. In addition, the pre-2000 data have been thoroughly addressed in a previous AHRQ Evidence-based Practice Center report⁹ and an extensive National Institute for Clinical Excellence (United Kingdom) report.^{8,49} In each section of the report, we describe previous systematic reviews that addressed the pre-2000 literature. Our search was not limited to English-language studies, since a significant proportion of the palliative care quality improvement studies have been conducted in non-US settings. We did not identify any eligible studies not published in English.

We included any timing of followup, including after-death interviews with families/caregivers. We addressed all settings, both inpatient and outpatient, as well as quality improvement interventions in inpatient or outpatient hospice or palliative care programs.

The detailed PICOTS criteria used for Key Questions 1 and 2 inclusion/exclusion for articles in this topic area follows:

Population(s)

We defined the relevant population as “...seriously ill patients and those with advanced disease (such as persons living with advanced cancer or intensive care unit patients at high risk of dying), who are unlikely to be cured, recover, or stabilize” (adapted from the National Consensus Project⁴¹).

Interventions

We included studies evaluating health care and palliative care interventions, including quality improvement interventions, such as patient education and self-management and provider audit and feedback.

Comparators

We included all comparators. For most studies, this was usual health care, but some studies tested interventions that were added on to usual hospice or palliative care.

Outcomes Measures for Each Key Question

For both Key Questions, we included all relevant patient or family/caregiver outcomes, including:

- Patient and family satisfaction/perceptions of palliative care.
- Patient symptoms, needs, distress, and quality of life.
- Health care utilization, such as hospital admissions or do-not-resuscitate orders (but not costs).
- Quality of care measures, such as timeliness of response to pain and other symptoms.

- Family/caregiver psychosocial symptoms, support, needs, quality of life, and grief/bereavement.

We excluded studies that did not report measurements of any of these outcomes or that only had outcomes not related directly to the target populations (e.g., staff knowledge or perceptions of care).

Timing

We included any timing of followup, including after-death interviews with families/caregivers.

Settings

We addressed all settings, both inpatient and outpatient, with a specific focus on the nursing home setting (primary) and hospice program setting (specialty), as underlined in the Analytic Framework (see column 4 in Figure 1).

Technical Expert Panel

We discussed areas of focus with the Technical Expert Panel, which included a number of stakeholder perspectives. These included researchers in the field of hospice and palliative care; representatives of different disciplines (e.g., social work, nursing) and key settings (nursing home, hospice, and intensive care); and payers.

Study Selection

Abstract Screen

Each abstract was independently screened by two reviewers. These reviewers included a trained article screener and a content expert. An abstract was excluded at this level if it was not a study of a health care or palliative care intervention, did not address palliative care populations, did not include patient and/or family outcomes in the results, or was not an included study design. (Appendix C, Abstract Review Form).

Abstracts were promoted to be screened using full text article if both reviewers agreed that the abstract could apply to one or more of the Key Questions. An abstract could be excluded for different reasons by the two reviewers. Disagreements about the eligibility of an abstract were resolved by discussion between the two reviewers or by adjudication of a third reviewer; this person was either a trained screener or a principle investigator on the project.

Article Screen

Full text articles underwent another independent review by paired investigators to determine whether they should be included in the full data abstraction (see Appendix C, Article Inclusion/Exclusion Form). If articles were deemed to have applicable information, they were included in the data abstraction. Articles could be excluded at this level for the same set of reasons used at the abstract screen level.

Articles were promoted to data abstraction if both reviewers agreed. An article could be excluded for different reasons by the two reviewers. Disagreements about the eligibility of an

article were resolved by discussion between the two reviewers or by adjudication of a third reviewer.

All screening was completed using the Distiller SR web-based systematic review software (Evidence Partners, Ontario, CA).

Data Abstraction

No forms were used for data abstraction in this systematic review. Due to the nature of the data (narrative), the senior investigators agreed that the data should be abstracted directly to tables. We used a consecutive two-reviewer process to abstract data from the included articles. In this process, a research assistant abstracted data directly to tables, and this data was checked by a senior investigator. Periodically, senior investigators cross-checked the work of the other senior investigators to ensure that abstractions were done appropriately. Reviewers were not masked to the articles' authors, institutions, or journal. Disagreements that could not be resolved between the reviewers were resolved through consensus adjudication at team meetings.

For all articles, reviewers extracted information on general study and population characteristics: population, disease, study settings, single vs. multi center, study design and description of the intervention. For study design, we classified all articles as RCTs and non-randomized controlled studies (almost all of which were pre-post or concurrent non-randomized controlled studies). Data abstracted on the interventions included: integrative vs. consultative, target of the intervention, and quality improvement elements. Outcomes included: sample size, disparities, specific outcome measure, other outcome measures and harms and benefits. We abstracted effect size whenever possible, and both numerical and statistical results. Since forms were not used for this phase of data abstraction, the elements that were abstracted can be seen in the evidence tables (Appendix E).

Risk of Bias Assessment of Individual Studies

We used a tool implemented successfully in past Evidence-based Practice Center projects, including the Cochrane Collaboration Tool for Assessing Risk of Bias from the Cochrane Handbook for Systematic Reviews of Interventions for assessing randomized controlled trials⁵⁰. Data abstraction forms were not developed for this phase of the review and elements of the data abstraction can be found in the evidence tables.

We assessed the risk of bias and appropriateness of all studies that met our eligibility criteria, following the guidance contained in chapter 6 of the AHRQ Methods Guide for Effectiveness and Comparative Effectiveness Reviews (hereafter, Methods Guide).⁵¹ We used a limited number of key criteria that are most appropriate for each study design and that are most important for determining the validity of the studies. After the pool of included articles in this review was determined, the core team of investigators determined that the Cochrane Collaboration tool⁵⁰ was most appropriate for all risk of bias assessments. Although we considered assessing risk of bias separately for non-randomized studies, we were unable to identify any validated tools that worked well in this literature and could be compared to risk of bias tools designed for randomized trials. The quality of individual studies was classified as "good," "fair," or "poor" based on the degree to which the studies adhered to the defined criteria. We did not factor in the quality score for blinding of the intervention; we did this because blinding of patients and personnel was generally not feasible in these interventions, but blinding of outcomes assessors would have been possible. A low risk of bias was assessed if six or more of the items were scored as a "yes." A medium risk of bias was assessed if four or five of the

items were scored as a “yes” or “unclear”. A high risk of bias was assessed if zero to three items were scored as a “yes.”

Applicability

To assess applicability, we used criteria stipulated in the Methods Guide^{1,51} and input from the expert panel concerning what criteria would be most useful to stakeholders. We addressed applicability in two ways. First, we assessed studies to ensure that they included a relevant palliative care population and outcome, as defined in the methods section on the population. For example, an intervention to improve advance directive completion by healthy patients might not translate well for ill cancer patients. An outcome of improved adherence to chemotherapy may not necessarily translate into improved quality of life. Secondly, to evaluate applicability for included studies, we extracted the relevant patient population (e.g., cancer type, stage, etc.) and setting (e.g., size, teaching vs. community hospital) information from each study in the evidence tables. For example, an intervention study on improving pain management in cancer patients may not translate well to the frail elderly, for whom the treatment of pain is very different. An intervention study that is successful in a hospital setting likely will not translate well to the nursing home setting. Finally, we abstracted details from articles about feasibility or setting-specific issues that could be relevant to translation to other settings.

Strength of the Body of Evidence

At the completion of our review, we assessed the quantity, quality, and consistency of the body of available evidence addressing Key Questions 1 and 2. We used the GRADE Working Group criteria adapted by AHRQ in its Methods Guide⁵¹ and published in the Journal of Clinical Epidemiology.⁵² We considered the strength of the study designs, with RCTs having the highest level of evidence, followed by non-randomized studies. If an outcome was evaluated by at least one randomized controlled trial in addition to non-randomized studies, our evidence grade was based on the randomized controlled trials, followed by the quality of the non-randomized studies. If an outcome was not evaluated in any randomized controlled trial, our evidence grade is based on the best available non-randomized study.

We assessed the strength of the best available evidence, including the risk of bias in relevant studies, as well as aspects of consistency, directness, and precision as described in the Methods Guide.^{51,52} As described in the Methods Guide, consistency was graded based on both the direction and range of effect size, including the percentage of studies with a statistically significant effect on the outcome. Directness was graded based on whether the measured outcome was directly related to patient-centered outcomes. In particular, health care utilization may be related to patient-centered outcomes, such as improved satisfaction with communication, but this relationship has not been established in the palliative care research literature, and utilization does not measure patient-centeredness directly. This outcome was therefore graded as indirect. Precision was graded only if the measurement tools and reporting of outcomes was homogenous enough to allow for quantitative synthesis; if not, precision was graded as not applicable. The direction of effect was listed for each (improvement with intervention if any of the studies showed improvement). The overall strength of evidence was then graded for each outcome, based on all of these different dimensions. For each outcome of interest, two investigators graded the major outcomes for each Key Question.

Unless otherwise noted, all strength of evidence assessments are for improvements to the outcome of interest.

Data Synthesis

We organized the review by target of the intervention, including a category for interventions that focused on multiple targets or targets other than the primary ones for this review, and evaluated each target category for applicability to each Key Question. Since many studies did not report effect size but only a p value, for each category, we calculated the percentage of studies with a statistically significant improvement in outcomes with the intervention compared to control. We also checked that all other studies did not report significant results in the opposite direction. Because the results of higher-quality studies might differ from those of lower-quality studies (more likely to have methodological issues and lower sample size), we evaluated for potential differences in results in two ways. In the grading process, we compared the strength of the evidence for both RCTs and non-RCTs. Also, because interventions on the organizational level often cannot be conducted as an RCT and these studies would therefore not be graded as high-quality, as a sensitivity analysis, for the target of continuity, we determined whether results of the evidence synthesis were different when including only the high- and medium-quality studies. To determine whether quantitative synthesis was appropriate, we evaluated the clinical and methodological diversity of studies, measurement tools, and outcome reporting, and assessed for evidence of selective outcome reporting and reporting of effect sizes or confidence intervals.

Peer Review and Public Commentary

Experts in palliative care in nursing home, hospice, and intensive care unit settings, as well as experts from the disciplines of nursing and social work and individuals representing stakeholder and user communities were invited to provide external peer review of this CER; AHRQ and an associate editor also provided comments. The draft report was posted on the AHRQ website for 4 weeks to elicit public comment. We addressed all reviewer comments, revising the text as appropriate, and documented everything in a disposition of comments report that will be made available 3 months after the Agency posts the final CER on the AHRQ website.

Results

Results of the Literature Search

The literature search process identified 13,014 unique citations. During the abstract review process, we excluded 12,567 abstracts that did not meet one or more of the eligibility criteria (see Methods for details). At article review, we excluded an additional 351 articles that did not meet one or more of the eligibility criteria (see Appendix D, Excluded Articles). Ninety studies described in 96 articles were eligible for inclusion in the review (Figure 2). We described the information abstracted in a systematic manner, but did not conduct any meta-analyses. The outcomes were too diverse to allow for quantitative synthesis.

Report Organization

We first divided the interventions into the four key target areas or into an additional category for multiple and other targets. The results section is organized into these five sections, by target area:

- Continuity, Coordination of Care, and Transitions
- Pain
- Distress
- Communication and Decisionmaking
- Interventions with multiple or other targets (this section also mostly details studies that fit into a narrower definition of quality improvement).

Each *target area* section is then further divided into subsections based on the Key Questions. Key Question 1a broadly addresses health care and palliative care interventions within the target area and their impact on outcomes and Key Question 1b addresses the settings of care. Key Question 2a addresses different quality improvement types and Key Question 2b addresses different models—integrative compared to consultative. Either Key Question 2a or 2b is then addressed for each section (whichever was most appropriate for the intervention types within that section—these were mutually exclusive).

The four sections focusing on individual targets are organized as follows:

- Study characteristics
- Key Question 1a (results for target): results summarized by key outcomes
- Key Question 1b: results for hospice and nursing home studies
- Key Question 2a (results for quality improvement types): results summarized by key outcomes (except for communication and decisionmaking, where Key Question 2b is addressed instead and a short summary of the results is given)
- Grading of the evidence
- Summary tables for the studies

For the last section on multiple and other targets focusing on quality improvement, since Key Question 1a was not analyzed, the results are organized somewhat differently, as follows:

- Study characteristics
- Key Question 1b: results for hospice and nursing home studies
- Key Question 2a: results summarized by quality improvement type

- Grading of the evidence
- Summary tables for the studies

Each section includes an assessment of the strength of evidence for Key Question 1 and 2, except for the strength of evidence for Key Question 1b, on settings. This strength of evidence is summarized in Appendix F.

Description of the Types of Studies Retrieved

There were 23 studies described in 26 articles that applied to continuity and addressed Key Questions 1a, 2 and 2a; 21 studies described in 23 articles applied to pain and addressed Key Questions 1a and 2a; seven studies described distress and addressed Key Question 1a; 20 studies described communication and addressed Key Questions 1a, 2a and 2b; 19 studies described in 20 articles described multiple and other targets and addressed Key Question 2a; two studies described in three articles discussed hospice and addressed Key Question 1b; seven studies discussed nursing homes and addressed Key Question 1b.

Continuity, Coordination of Care, and Transitions

Study Characteristics

We found 23 studies detailed in 26 articles addressing this target. The 23 studies were published between the years 2000 and 2011 and had sample sizes in the range of 40 to 710 patients with 17 studies (74 percent) between 100 and 300 patients. Of the 23 studies, 12 were randomized clinical trials (RCTs) and 11 were non-RCTs. Of the 11 non-RCTs, seven were before-after studies conducted in the same setting with a different set of patients as the control group. Five studies were conducted in an inpatient setting, four in a home care setting, four in an ambulatory setting, three in nursing homes, one in hospice, one in a rehabilitation unit, and five in mixed settings. Fifteen studies (65 percent) were multicenter studies. One study reported only within-group comparisons and therefore the outcomes are not further analyzed here⁵³ (Table 3, Appendix E, Evidence Table 1). All studies compared the intervention to usual care.

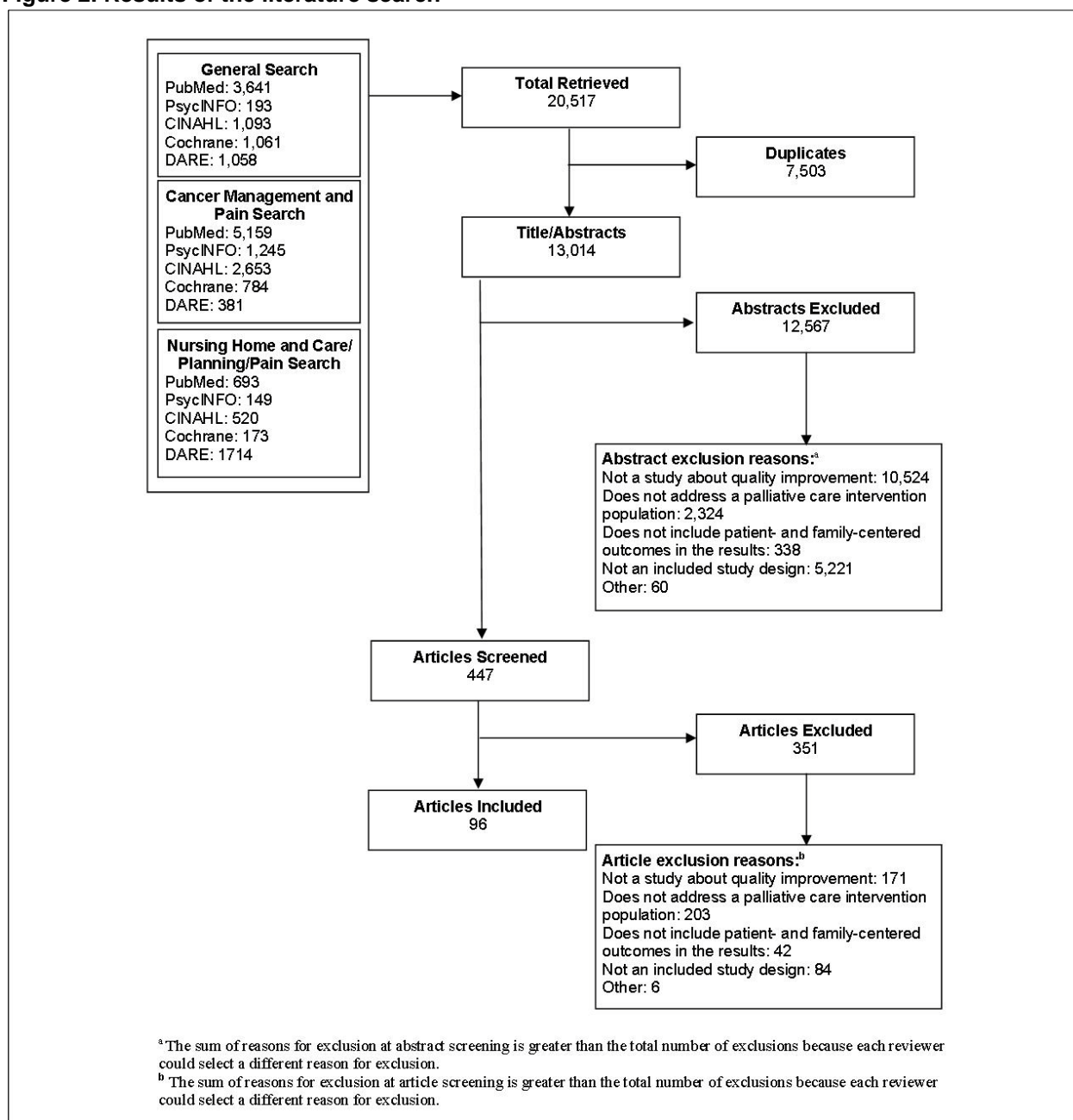
The populations in these studies were adults with a mean age (by study) between 62 and 84. Most of the studies included patients with mixed illnesses (n=9) or cancer patients only (n=7). Five studies focused on cancer, chronic obstructive pulmonary disease or chronic heart failure patients, one study included dialysis patients, and one included chronic heart failure and chronic obstructive pulmonary disease patients. None of the studies reported anything on disparities (Table 3, Appendix E, Evidence Table 1).

In 20 (87 percent) of studies, the interventions addressed multiple targets of palliative care. All but two included targets of coordination of care or an interdisciplinary team as part of the intervention. The two studies^{54,55} that did not include one of these targets focused on facilitated referrals to hospices. In 11 studies, the existing staff provided the intervention, in nine studies an external team or consultant provided the intervention, and in three studies a mix of these two provided the intervention. Studies addressed a wide range of interventions and outcomes, and quantitative synthesis was judged not to be appropriate due to this diversity (Table 3, Appendix E, Evidence Tables 2 and 3).

Risk-of-bias (ROB) scores were high for 10 studies, medium for eight, and low for five. Eleven of the studies were non-RCTs, some RCTs did not adequately report the randomization

process, and most did not report blinding of outcome assessment (Appendix E, Evidence Table 4).

Figure 2. Results of the literature search



Key Question 1. What is the effectiveness of health care and palliative care interventions for improving the quality of palliative care?

Key Question 1a. Specific Targets

See Figure 1, Framework, column 3, for a listing of targets.

Key Points

There was a moderate strength of evidence for improvement in satisfaction, based on six medium-quality studies for patients and four for caregivers, both with consistent results.

Patient Quality of Life and Satisfaction

Nine studies evaluated quality of life (QOL) of patients;⁵⁶⁻⁶⁴ eight were RCTs. Only three studies (33 percent) showed a statistically significant improvement in patient QOL with the intervention.^{57,58,64} Whether or not the instrument used for QOL measurement was specifically designed for that population had no influence on the results. In addition, the sample size was the same in the studies that showed an effect compared to the studies showing no effect. Also, neither the intervention targets nor the setting explained the likelihood of a significant finding (Table 4, Appendix E, Evidence Table 5).

Seven studies assessed patient satisfaction (every study used a different satisfaction scale).^{58,62,63,65-68} Four studies were RCTs. One study reported within-group comparison only, and was therefore not included in the analysis.⁶⁵ Of the other six studies, four (67 percent) showed statistically significant effects for this outcome in favor of the intervention.^{62,65,67,68} The quality of the studies, the sample size, the settings and the target of intervention did not influence the likelihood of a significant finding (Table 4; Appendix E, Evidence Table 1 though 4).

Three studies measured both patient satisfaction and QOL.^{58,62,63} Findings for the two outcomes were different for two of the studies (one statistically significant, one not) and the same for only for one study⁶³ (both were not statistically significant) (Table 4, Appendix E, Evidence Table 5).

Five out of seven studies that reported significant improvement in QOL or satisfaction in the intervention group included coordination of care processes in the intervention. On the other hand, only one of four studies not using coordination of care processes showed significant results in one of these outcomes (Table 4, Appendix E, Evidence Table 5).

Caregiver Satisfaction, Quality of Life, and Burden

Six studies reported caregiver satisfaction.^{58,68-71} Four of these studies (67%) showed statistically significant improvement with the intervention,^{58,68,70} including three RCTs and a non-RCT. The targets of the interventions and the sample size were comparable among the studies. The instruments used to measure satisfaction had no influence on the likelihood of a statistically significant finding. One study with a positive result on satisfaction evaluated grief as well, which showed no difference between the groups (Table 4, Appendix E, Evidence Table 5).⁷²

Only one study reported caregiver QOL.⁶⁸ This study evaluated QOL with two different instruments and both showed statistically significant improvement with the intervention. Three studies reported caregiver burden;^{58,61,69} two were RCTs. None of the studies showed a significant difference between the intervention and control group (Table 4, Appendix E, Evidence Table 5).

Among the three studies evaluating at least two of these three outcomes, two had conflicting findings for the different outcomes and one had a similar finding among outcomes; in that study, neither caregiver burden or satisfaction showed a statistically significant improvement with the intervention (Table 4, Appendix E, Evidence Table 5).⁶⁹

Symptoms

Eight studies in the target of continuity, coordination, and transitions assessed patient symptoms;^{56,57,60,63,64,68,69,73} five were RCTs. None of the studies showed statistically significant improvement of overall symptoms in the intervention group versus the control group. In five of these eight studies,^{57,60,63,64,68} a specific symptom showed a statistically significant improvement in the intervention compared to the control group: in three RCTs,^{57,60,64} there was a statistically significant improvement with the intervention on depression symptoms; one non-RCT reported a statistically significant improvement for dyspnea, and another non-RCT showed a statistically significant improvement for pain. (Table 4, Appendix E, Evidence Table 5).

Health Care Utilization (Decreased Admissions or Length of Stay, Increased Hospice Referral)

Sixteen studies reported impact on health care utilization,^{56-58,62,64-66,68-69,71-72,74-76} characterized by length of stay or different types of admissions; one did not report statistics on the results. Seven of these studies were RCTs. Only five of the 16 studies (31 percent) reported a statistically significant improvement with the intervention compared to the control group (four decreased admissions or length of stay, and one improved hospice referral.^{54,65,66,68,74} (Table 4, Appendix E, Evidence Table 5).

Location of Death

Six studies reported location of death (e.g., whether the patient died at home or in his or her preferred location),^{54,64,69,74,77-78} three of which were RCTs. In three studies (50 percent), two of which were RCTs, the intervention had a statistically significant impact in the percentage of patients who died at home or in their preferred location.^{64,74,78} The sample sizes and patient mix were comparable among all studies (Table 4, Appendix E, Evidence Table 5).

Specialized Palliative Care Usage

Four studies reported enrollment in hospices, use of hospice services or placing patients on a comfort care plan.^{54,55,64,75} One RCT, which focused on the outcome of improving hospice referrals in nursing homes, reported significant results in favor of the intervention at 30 days but not at time of death.⁵⁴ A non-randomized study⁵⁵ and a RCT⁶⁴ (of a broader intervention and not powered for this outcome) reported non-significant results, while another very small non-RCT reported significant results in favor of the intervention. (Table 4, Appendix E, Evidence Table 5)⁷⁵

Key Question 1b. Specific Settings

Key Points

Too few studies to draw conclusions in the hospice or nursing home setting.

One study was conducted in hospice and four included the nursing home setting (Table 4, Appendix E, Evidence Table 5); there were too few studies in these settings to draw conclusions.

An RCT of systematic feedback of standardized assessments and interdisciplinary team discussions in hospices⁶⁰ found a statistically significant improvement with the intervention in patient depression, but not in patient symptoms or caregiver depression (Table 4, Appendix E, Evidence Table 5).

Three studies evaluated care pathways in nursing homes, and one focused on increasing hospice referrals. A 2010 non-RCT evaluated the Liverpool Care Pathway for the Dying Patient across hospital, nursing home, and home settings; among the 80 nursing home patients included, the intervention did not significantly increase the quality of care measure of do-not-resuscitate orders. A 2009 study of the Gold Standards Framework,⁷⁴ addressing symptoms, needs, and coordination in 49 nursing homes, found statistically significant reductions in deaths in the nursing home and crisis hospitalizations with the intervention. A multicenter study of a different care pathway in nursing homes found no improvement in bereaved families' satisfaction.⁷¹ Finally, Casarett et al.⁵⁴ conducted an RCT identifying nursing home residents appropriate for hospice care and communicating this information to their physicians. The intervention resulted in statistically significant improvements in hospice enrollment (1 percent for the control group compared to 20 percent for the intervention group, $p=0.001$) and patient satisfaction, and found statistically significant decreases in hospital utilization (Table 4, Appendix E, Evidence Table 5, Appendix F).

Key Question 2. What is the evidence for different quality improvement models for improving palliative care?

Key Question 2a. Different Types of Quality Improvement Interventions

Key Points

Six of the nine studies (67%) using patient-centered quality improvement types such as patient/family/caregiver education and promotion of self-management showed a significant improvement with the intervention for the outcomes of patient quality of life or satisfaction, compared to three of nine studies (33%) using provider-centered interventions.

Quality Improvement Types

The interventions in the studies for continuity, coordination, and transitions included between one and five quality improvement (quality improvement) types (for details see methods, Table 2); 13 (57 percent) included three or four quality improvement types. Fifteen studies included organizational change; 13 included facilitating relay of clinical data to providers; nine included promotion of self-management or patient/family/caregiver education; nine included provider reminder systems and provider education; and four included training for implementation of quality improvement (Table 4, Appendix E, Evidence Tables 2 and 3).

Patient Quality of Life and Satisfaction

Of the nine studies^{56-59,63-64,66-68} identified that used patient-centered quality improvement types such as patient/family/caregiver education and promotion of self-management, six (67 percent) showed a significant effect in favor of the intervention on satisfaction or QOL. One of the three non-significant studies reported that some of the control group received specialized palliative care as well.⁵⁹ Of the ten studies^{56,59-63,66-68} using provider-centered interventions (such as provider reminder systems, facilitated relay of clinical data to providers, or provider education), only three (30 percent) had a significant effect on QOL or satisfaction in favor of the intervention. All three studies that did show an effect of the intervention also included patient-centered quality improvement types (Table 4, Appendix E, Evidence Table 5).

Caregiver Satisfaction, Quality of Life, and Burden

Of the three studies using patient and family-centered quality improvement types (such as patient/ family/ caregiver education and promotion of self-management), all showed a statistically significant improvement in caregiver satisfaction with the intervention.^{58,68,72} The three studies showing no effect on any of these three outcomes were studies that included only provider-centered quality improvement types or organizational change, and did not include patient- and family-centered quality improvement types^{61 69} (Table 4, Appendix E, Evidence Table 5).

Symptoms

The eight studies for the targets of continuity, coordination, and transitions which evaluated overall symptoms as an outcome, which showed no statistically significant impact from the intervention, most commonly included the following quality improvement types: facilitated relay of clinical data to providers (seven studies), organizational change (six studies), provider reminder systems (five studies), and patient/family/caregiver education (five studies) (Table 4, Appendix E, Evidence Table 5).

Health Care Utilization (Decreased Admissions or Length of Stay, Increased Hospice Referral)

Of the 16 studies reporting statistics which evaluated this outcome, seven used the quality improvement type provider education. Of these seven studies, four (57 percent)^{65,66,68,74} found a statistically significant improvement in health care utilization (decreased admissions or length of stay) in the intervention compared to the control group. Also, two of four studies (50 percent) using provider reminder systems^{68,74} in the intervention and two of three studies (66 percent) using quality improvement training to implement the intervention^{68,74} reported a significant improvement with the intervention. Only three of the nine studies using the quality improvement type facilitated relay of data to providers^{54,68,74} were associated with significant results. Studies using patient-centered quality improvement strategies like patient/family/caregiver education and promotion of self-management reported a statistically significant improvement in utilization outcomes with the intervention in only three of the eight (38 percent) of the studies.^{65,66,68} Three of the ten studies (30 percent)^{65,66,74} which used some version of organizational change found a statistically significant improvement (Table 4, Appendix E, Evidence Table 5).

Specialized Palliative Care Usage and Location of Death

We did not find any association between quality improvement strategies and study findings for the outcome of specialized palliative care usage or location of death.

For all outcomes, when including only the results of the high- and medium-quality studies (excluding the low-quality studies), the overall findings were consistent.

Key Question 2b. Different Models in Palliative Care: Integrative Compared With Consultative

This Key Question was not analyzed for this target.

Grading of the Evidence

Risk of bias was generally low to medium for RCTs and medium to high for non-RCTs. All outcomes were direct except health care utilization, which was graded as indirect because it is

considered a surrogate outcome in palliative care, and has not been shown to be directly related to patient-centered outcomes such as satisfaction. Precision was not applicable due to diversity of outcomes measurement tools, and study diversity was high for all outcomes, with a wide variety of different types of interventions. Study results did not generally differ between the RCTs and non-RCTs or between high-and medium- and low-quality studies. For QOL, most studies were RCTs with medium risk of bias and evidence was inconsistent. For patient satisfaction, evidence was consistent for both RCTs and non-RCTs. For caregiver burden, evidence was consistent for the two RCTs; for caregiver satisfaction, evidence was consistent for both the RCTs and the non-RCTs. For symptoms, evidence was consistent for the five RCTs and consistent for the three non-RCTs. For health care utilization, evidence was consistent for both the RCTs and non-RCTs. Strength of evidence was low across all outcomes except for satisfaction, where it was moderate. (Table 5).

Table 3. Overview of characteristics of studies addressing continuity

Author/Year/ refID	Study Design Sample Size	Population (disease, mean age)	Setting(s)	Description of Intervention
Aiken, 2006 ⁵⁶	RCT 192	COPD, CHF 69	Home care	Home-based case management by nurse case managers, in coordination with patients' existing source of medical care
Badger, 2009 ⁷⁴	Non-RCT 437	Mixed illnesses, no age reported	Nursing home	Gold Standards Framework in Care Homes - Identifying, assessing and treating needs and symptoms, Improving coordination within institution and outside
Bailey, 2005 ⁷⁷	Non-RCT 203	Mixed illnesses 68	Hospital	Inpatient Comfort Care Program - Staff education and support to identify actively dying patients and implement comfort care order set template
Bakitas, 2009 ⁵⁷	RCT 322	Mixed cancer 65	Ambulatory	Multicomponent telephone-based intervention- Education, encourage patient activation, self-management, and empowerment
Bookbinder, 2005 ⁵³	Non-RCT 257	Mixed illnesses >70	Hospital,	Palliative Care for Advanced Disease (PCAD) pathway - daily flow sheet, standard orders for symptom control
Brumley, 2003 ⁶⁵	Non-RCT 300	COPD, CHF, cancer 74	Home care	Home-Based Palliative Care - Care team (physician, nurse, social worker) assesses, coordinates and manages care
Brumley, 2007 ⁶⁶	RCT 297	COPD, CHF, cancer 72	Home care	As above
Casarett, 2005 ⁵⁴	RCT 205	Mixed illnesses 84	Nursing home	Structured interview and notification of residents' physicians about residents' preference for hospice care
Cohen, 2010 ⁵⁵	Non-RCT 133	Dialysis patients with poor prognosis 70	Ambulatory	Intervention to facilitate hospice referral - Renal supportive care teams encouraged care planning, discussed hospice resources, offered general support
Dudgeon, 2008 ⁶⁹	Non-RCT 200	Mixed cancer 66	Ambulatory, hospital, home care	Palliative care integration project - Implementation of assessment tools, collaborative care plans, symptom management guidelines

Table 3. Overview of characteristics of studies addressing continuity (continued)

Author/Year/ refID	Study Design Sample Size	Population (disease, mean age)	Setting(s)	Description of Intervention
Engelhardt, 2006 ⁶⁷	RCT 275	COPD, CHF mixed cancer 70	Hospital, home care	Advanced illness coordinated care program- 6 sessions with care coordinator who helps with provider communication, care coordination, support
Hughes, 2000 ⁵⁸	RCT 188	Mixed illnesses 70	Home care	Team-Managed Home-Based Primary Care - care manager, 24-hour contact, prior approval of hospital readmissions, discharge planning
Jordhoy, 2000 ⁷⁸ , 2001 ⁵⁹ , Ringdal 2002 ⁷² , 2001 ^{79*}	RCT 434	Mixed cancer 68	Home care, ambulatory, palliative medicine unit	Comprehensive palliative care - All in- and outpatient services occurred on Palliative Medicine Unit, Unit staff served as link to community, predefined guidelines, educational programs for community
Luhrs, 2005 ⁷⁵	Non- RCT 39	Mixed illnesses 72	Hospital	Palliative Care for Advanced Disease (PCAD) pathway - daily flow sheet, standard orders for symptom control
McMillan, 2011 ⁶⁰	RCT 709	Mixed cancer 73	Hospice	Systematic feedback of assessment to interdisciplinary teams (IDTs) - Standardized assessment followed by two interdisciplinary team (IDT) discussions
Mitchell, 2008 ⁶¹	RCT 159	Mixed illnesses 65-72	Ambulatory, hospital	Specialist-general practitioner case conferences: General practitioner phoning in to a routine specialist team meeting
Moore, 2002 ⁶²	RCT 202	Lung cancer 67	Ambulatory	Nurse led followup: Nurse specialists assessed patients monthly or as needed by phone or in clinic
Pantilat, 2010 ⁷³	RCT 107	CHF, COPD, mixed cancer, Cirrhosis 76	Hospital	Hospital-based palliative care consultation: daily during hospitalization, palliative care physician assessed patient, discussed treatment preferences
Rabow, 2004 ⁶³	Non- RCT 90	COPD, CHF, cancer 68	Ambulatory	Comprehensive care team - Primary care physician received palliative care team consultations, patients received care planning, psychosocial support, family caregiver training.
Reymond, 2011 ⁷¹	Non- RCT 299	Mixed illnesses Not reported	Nursing home	Residential aged end-of-life care pathway - Identifying and training nurse champions, networking facilities with specialty palliative care, educating physicians, development and implementation of end-of-life clinical management care pathway
Woo, 2011 ⁶⁸	Non- RCT 169	Mixed illnesses (majority dementia) 84	Rehabilitation and convalescent unit	Continuous quality improvement initiative (Plan-do-study-act) - Service reengineering, provision of guidelines, educational material, and interactive sessions to achieve culture change
Temel, 2010 ⁶⁴	RCT 151	Metastatic lung cancer 65	Ambulatory	Early palliative care integrated with standard oncologic care - Palliative care physician/advance practice nurse consult within 3 months of diagnosis and then monthly; addressed physical and psychosocial symptoms, goals of care, treatment decisionmaking, coordination
v.d Heide, 2010 ⁸⁰	Non- RCT 298	Mixed cancer 64-75	Hospital, nursing home, home care	Liverpool Care Pathway for the Dying Patient - Structuring care, facilitating audit by standardizing the monitoring of care

Abbreviations: RCT = randomized controlled trial; CHF = chronic health failure; COPD = chronic obstructive pulmonary disease

*Multiple publications on the same study

Table 4. Outcomes of studies addressing continuity

Author, Year	Study Design; Sample Size	ROB	Results Statistically Significant Improvement With the Intervention vs. the Control Group			
			<i>Patient QOL; Caregiver Burden or QOL</i>	<i>Patient Satisfaction; Family Satisfaction</i>	<i>Symptom Control</i>	<i>Health Care Utilization</i>
Aiken, 2006 ⁵⁶	RCT 192	Low	No		No	No
Badger, 2009 ⁷⁴	Non-RCT 437	High				Yes
Bailey, 2005 ⁷⁷	Non-RCT 203	Medium				No
Bakitas, 2009 ⁵⁷	RCT 322	Medium	Yes		No	No
Bookbinder, 2005 ⁵³	Non-RCT 257	High				No between group significance testing
Brumley, 2003 ⁶⁵	Non-RCT 300	Medium		No between group significance testing		Yes
Brumley, 2007 ⁶⁶	RCT 297	Low		Yes		Yes
Casarett, 2005 ⁵⁴	RCT 205	Low		Yes		Yes (hospice referral)
Cohen, 2010 ⁵⁵	Non-RCT 133	High				No
Dudgeon, 2008 ⁶⁹	Non-RCT 200	High	n/a No	No	No	No
Engelhardt, 2006 ⁶⁷	RCT 275	High		Yes		
Hughes, 2000 ⁵⁸	RCT 188	Medium	Yes; No	No; Yes		No
Jordhoy, 2000 ⁷⁸ , 2001 ⁵⁹ , Ringdal 2002 ⁷² , 2001 ⁷⁹	RCT 434	High	No	Yes		No
Luhrs, 2005 ⁷⁵	Non-RCT 39	Medium				No
McMillan, 2011 ⁶⁰	RCT 709	High	No		No	
Mitchell, 2008 ⁶¹	RCT 159	Low	No No			
Moore, 2002 ⁶²	RCT 202	Low	No	Yes		No

Table 4. Outcomes of studies addressing continuity (continued)

Author, Year	Study Design; Sample Size	ROB	Results Statistically Significant Improvement With the Intervention vs. the Control Group			
Pantilat, 2010 ⁷³	RCT 107	High			No	
Rabow, 2004 ⁶³	Non-RCT 90	Medium	No	No	No	No
Reymond, 2011 ⁷¹	Non-RCT 299	High		No		No significance testing
Woo, 2011 ⁶⁸	Non-RCT 169	High	N/A No	Yes	No	Yes
Temel, 2010 ⁶⁴	RCT 151	High	Yes		Yes (only depression measured)	No for all Yes for patients who died
v.d Heide, 2010 ⁸⁰	Non-RCT 298	High	None of these outcomes measured			

Abbreviations: RCT = randomized controlled trial; QOL = Quality of life; COPD = chronic obstructive pulmonary disease; CHF = chronic heart failure; ROB = risk of bias

Table 5. Evidence grading for continuity (KQ1a and KQ2a)

Number of Studies; Subjects	Domains Pertaining to Strength of Evidence, by Key Outcomes				Strength of Evidence That the Intervention Improved Outcomes Compared With the Control Group
	Risk of bias	Consistency	Directness for outcome	Precision; Study diversity	
Patient QOL					Low SOE
8; 2562	RCT/ medium	Inconsistent	Direct	not applicable; high	Low
1; 90	Non-RCT/ medium	Not applicable	Direct	not applicable; not applicable	Low
Patient Satisfaction					Moderate SOE
4; 962	RCT/ medium	Consistent	Direct	not applicable; high	Moderate
3; 559	Non-RCT / high	Consistent	Direct	not applicable; high	Low
Caregiver Burden					Low SOE
2; 448	RCT/ medium	Consistent	Direct	not applicable; high	Low
1; 200	Non-RCT / high	Not applicable	Direct	not applicable; not applicable	Low
Caregiver Satisfaction					Low SOE
3; 472	RCT/ medium	Consistent	Direct	not applicable; high	Low
3; 668	Non-RCT / high	Consistent	Direct	not applicable; high	Low
Symptoms					Low SOE
5; 1481	RCT/ medium	Consistent (no effect)	Direct	not applicable; high	Low
3; 459	Non-RCT / high	Consistent (no effect)	Direct	not applicable; high	Low
Health Care Utilization*					Low SOE
7; 1641	RCT/medium	Inconsistent	Indirect for surrogate outcome	not applicable; high	Low
6; 1634	Non-RCT /high	Inconsistent	Indirect for surrogate outcome	not applicable; high	Low

* admissions, length of stay, interventions

Abbreviations: KQ=Key Question; SOE = strength of evidence; RCT= randomized controlled trial; QOL = quality of life

Pain

Study Characteristics

The 21 included studies described in 23 articles spanning the years 2000 to 2011. The median sample size was 105 patients (range: 43-187). Sixteen studies examined mixed cancer populations, while one study examined gynecologic cancers,⁸¹ two studies examined lung cancer only,^{82,83} and two focused on patients with severe dementia.^{84,85} Sixteen studies were conducted in an ambulatory setting, two were conducted in nursing homes,^{84,85} two in home care,^{86,87} and one in a hospital.⁸⁸ Mean age of study participants ranged from 52 years to approximately 86.5

years of age, with a median of 59.7 years of age. Median followup time following the initiation of the intervention was eight weeks (range: 2-24 weeks), excluding one study⁸⁹ which performed followup to the patient's death. Fourteen out of the 21 studies were conducted in the United States (67 percent), two studies were conducted in Canada,^{84,86} one in Australia,⁸⁸ one in Italy,⁸⁹ and three in the Netherlands (Table 6, Appendix E, Evidence Tables 1, 6 and 7).^{87,90}

Out of the 21 studies, 18 (86 percent) were RCTs. Nineteen randomized at the patient level, one study randomized by institution block,⁹¹ and one study randomized by nursing home unit level.⁸⁴ The three remaining studies used non-equivalent control groups.^{83,86,92} Six studies were conducted in a single setting, and 15 were conducted in multiple settings, ranging from two to 21 sites.^{83,92} All compared the intervention to usual care. Patient pain was the target in all 21 (100 percent) of the studies (Table 6, Appendix E, Evidence Tables 1, 6 and 7).

Five of the studies (24 percent) used facilitated relay of data to providers as a quality improvement element.^{83,84,87,89,93,94} Five studies (24 percent) used provider education as a component of the intervention,^{83,85,86,91,95} while 18 studies (86 percent) employed patient, family, and/or caregiver education. Five of these studies utilized print and video materials to enhance the educational intervention.^{86,87,93,96,97,98} One study used print material alone,⁸¹ and one study used video material alone.⁸²

Risk-of-bias scores were high for five studies, medium for six, and low for ten. Three of the studies were non-RCTs, some RCTs did not adequately report the randomization process, and many did not report blinding of outcome assessment (Table 6, Appendix E, Evidence Table 8).

Key Question 1. What is the effectiveness of health care and palliative care interventions for improving the quality of palliative care?

Key Question 1a. Specific Targets

See Figure 1, Framework, column 3, for a listing of targets.

Key Points

There was a moderate strength of evidence for outcome of improvement in pain, based on 21 medium-quality studies (18 RCTs) with inconsistent results; 18 of the studies were patient/caregiver education/self-management.

Pain

All 21 included studies assessed pain as an outcome. Fourteen out of 21 studies (67 percent) used the Brief Pain Inventory (BPI) as the pain measurement tool. One study⁸³ used the Quality of Life Scale/Cancer Patient Tool, one study⁹⁵ used the Symptom Experience Scale, one study⁸⁹ used a visual analog scale, and one⁸² used the McGill Pain Questionnaire. One other study used treatment data to determine patient pain experience.⁹² Of the two studies focusing on dementia, one study⁸⁴ used the Pain Assessment Checklist for Seniors with Limited Ability to Communicate, and the other used the Discomfort-Dementia of the Alzheimer's Type. (Table 7, Appendix E, Evidence Table 9).⁸⁵ Additional issues with outcome reporting of these studies that precluded quantitative synthesis included inconsistent reporting of the BPI, which raised concerns for selective outcome reporting (e.g., only nine of the 14 studies reported average pain). Only five of the studies reported confidence intervals or effect sizes, and reported time to outcome also varied. (Table 8)

Ten of the 21 studies showed statistically significant improvement with the interventions on pain scores compared to the control group. This was similar for small studies (<100) and larger studies (100-200, 5 of 11 (45%) showed significant improvement). Types of reported pain scores measured by the BPI included worst pain, average pain, usual pain, current pain, least pain, pain relief, and pain interference. Of those studies using the BPI to measure pain outcomes, two studies^{88,93} demonstrated significant improvement with the interventions on both average and worst pain scores, two studies^{87,99} showed significant differences by group on scores for current pain, three studies found significant effects for usual or average pain.^{86,91,96} and one study found significant effects for average and current pain.⁹⁰ Two studies, which used visual analog scales to measure pain rather than the BPI, found significant pain improvements in the intervention group relative to controls. (Table 7, Appendix E, Evidence Table 9).^{85,89}

Among interventions with significant impact on patient pain outcomes, number of encounters ranged from one^{86,88} to six.⁹³ Among those interventions shown to have no significant impact on pain outcomes, number of encounters ranged from one¹⁰⁰ to 10.⁸⁴ Of the seven effective interventions that targeted patients and caregivers, four (57 percent) were conducted in ambulatory settings,^{88,90,96,99} two in home care,^{86,87} and one in a hospital.^{93,94} Only two studies out of the eight showing a significant improvement with the intervention were conducted at a single site^{89,90} (Table 7, Appendix E, Evidence Table 9).

Quality of Life

Nine of the 21 (43 percent) studies measured QOL as an outcome. Of these nine studies, only one^{93,94} found any improvement with the intervention on QOL. Moreover, this study only found an improvement on a single sub-scale of a quality of life measure. There was no consistency among these eight studies in the measurement of QOL; every study used a different instrument. Even in the cases where the intervention demonstrated significant positive outcomes for pain, there were no commensurate significant gains in QOL (Table 7, Appendix E, Evidence Table 9).

Key Question 1b. Specific Settings

No studies were in the hospice setting. Two studies targeted pain in nursing homes. One multicenter RCT of 21 nursing units evaluated routine observational pain assessment checklist for patients with dementia;⁸⁴ the study found a statistically significant improvement with the intervention for pain medication use. The study did not report the impact of the intervention on patients' pain. A multicenter RCT in 14 nursing homes that looked at implementation a protocol for assessing discomfort found a significant improvement with the intervention both on nurses' assessments and on patient discomfort (Table 7, Appendix E, Evidence Table 9, Appendix F).

Key Question 2. What is the evidence for different quality improvement models for improving palliative care?

Key Question 2a. Different Types of Quality Improvement Interventions

Key Points

Eighteen of the 21 studies targeting pain used patient/family/caregiver education and/or promotion of self-management as quality improvement types.

Patient, Family, and/or Caregiver Education

All studies that used patient, family, and/or caregiver education also used promotion of patient/caregiver self-management. One study⁸² used a patient and caregiver reminder system as a component of the intervention. One study⁸³ used organizational change in their intervention. None of the studies used financial incentives, regulations or policy to affect pain outcomes (Table 7, Appendix E, Evidence Table 9).

Among those 18 studies that used patient, family, and caregiver education and promotion of self-management, 12 of the studies included multiple contacts with the patient.^{82,87,90,92,93-95,97,98,101,102-104} The number of followup contacts among these studies ranged from one brief 10-minute followup⁹⁶ or followup phone call⁹⁷ to 10 individual contacts over the course of 20 weeks⁹⁵ (Table 7, Appendix E, Evidence Table 9).

The majority (86 percent) of the studies examined patient-directed educational interventions. Three studies focused on provider-level interventions only. One of these studies⁸⁹ focused on the use of strong opioids as first-line therapy in cancer pain management as the intervention under study, one⁹¹ employed a provider education program about using an algorithm to improve cancer pain management, and one⁸⁵ used a serial trial intervention--a protocol for assessing the needs of people with dementia (Table 7, Appendix E, Evidence Table 9). The nine studies demonstrating a significant positive impact of interventions on patient pain outcomes varied in scope, intensity, and target of intervention. Moreover, studies were diverse in the respect that interventions were delivered at different points in patients' illness trajectories, and study participants varied in health status at the time of the interventions. Three of these studies focused on provider behavior. One study⁹¹ implemented a provider training program to improve provider adherence to a previously tested cancer pain management algorithm. The other provider-focused study used a systems-change approach (testing the efficacy of using strong opioids as first-line therapy in cancer pain management, relative to the WHO Analgesic Ladder⁸⁹), and the other used a serial-trial intervention to help nurses and staff assess unmet needs of patients⁸⁵. The other seven studies demonstrating improvements in pain management focused on patient and caregiver education and promotion of self-management (Table 7, Appendix E, Evidence Table 9).

Eight studies focused on patient, family, and caregiver education as well as promotion of self-management.^{86-88,90,93,96,97,105} In addition to patient education and promotion of self-management, two of these studies also included facilitated relay of clinical data to providers,^{87,93} and one also included pain consultation.⁹⁰ One study included provider education in addition to patient education and promotion of self-management.⁸⁶ Of the three positive studies not including patient and caregiver education, two included provider education alone,^{85,91} and the other consisted of facilitated relay of clinical data to providers (Table 7, Appendix E, Evidence Table 9).⁸⁹

Key Question 2b. Different Models in Palliative Care: Integrative Compared With Consultative

This Key Question was not analyzed for this target.

Grading of the Evidence

Risk of bias was low for RCTs and medium for non-RCTs. Precision was not applicable because study results could not be quantitatively combined; outcomes were reported differently and effect sizes were not reported consistently. Study diversity was moderate for both outcomes; although almost all populations were mixed cancer and interventions focused on patient

education, the timing, nature, and scope of the interventions was relatively diverse. Because of their patient-centeredness, both outcomes were direct: pain interventions should impact directly on pain outcomes, and pain is also an element of many QOL measurement tools and directly affects quality of life. For pain, a direct outcome, most studies were RCTs and evidence was inconsistent in the direction of improvement, and for QOL, all studies were RCTs and evidence was consistent with no effect. Strength of evidence was moderate for pain, given directness and relatively consistent results, and low for quality of life given consistent findings of no effect. (Table 9).

Table 6. Characteristics of studies targeting pain

Author/Year	Study Design	Sample Size*	Setting	Intervention
Anderson 2004 ¹⁰⁶	RCT	97	Ambulatory	Patient education consisting of race- and gender-tailored video, followed by a nurse-led meeting and a followup call.
Aubin, 2006 ⁸⁶	Non-RCT	80	Home care	One-time educational intervention
Borneman, 2008 ⁸³	Non-RCT	46	Ambulatory	Four-part educational intervention
Borneman, 2010 ⁹²	Non-RCT	157	Ambulatory	Four-part educational intervention
Dalton, 2004 ¹⁰⁴	RCT	127	Ambulatory	Profile-tailored CBT treatment program
Du Pen, 2000 ⁹¹	RCT	105	Ambulatory	Provider focused education intervention on implementing a previously tested algorithm for cancer pain management
Fuchs-Lacelle, 2008 ⁸⁴	RCT	173	Nursing Home	Nurse-led systematic pain assessment
Given, 2002 ⁹⁵	RCT	113	Ambulatory	Ten-part nurse-implemented pain and fatigue management educational intervention
Keefe, 2005 ¹⁰²	RCT	78	Home care	Three-session nurse-led partner-guided pain management intervention
Kovach 2006 ⁸⁵	RCT	114	Nursing Home	Serial trial intervention, a protocol of assessing needs of people with dementia
Lovell, 2010 ⁸⁸	RCT	185	Hospital	Pain management educational intervention utilizing a booklet and a video
Marinangeli, 2004 ⁸⁹	RCT	92	Ambulatory	Use of strong opioids as first line therapy
Miaskowski, 2004 ⁹³ and Miaskowski 2007 ^{94**}	RCT	174 167	Ambulatory	Six-week nurse-led psychoeducational intervention
Oldenmenger 2011 ⁹⁰	RCT	72	Ambulatory	Pain consult plus specialized nurse-conducted patient education program (PEP).
Oliver, 2001 ⁹⁹ Kalaualani, 2007 ^{107**}	RCT	67	Ambulatory	One-time individualized education and coaching session
Syrjala, 2008 ⁹⁶	RCT	78	Ambulatory	Patient training in cancer pain management using integrated print and video materials
van der Peet, 2004 ⁸⁷	RCT	120	Home care	Three-visit nurse-led pain education program
Ward, 2000 ⁸¹	RCT	43	Ambulatory	Nurse-led individually tailored information
Ward, 2008 ¹⁰⁰	RCT	176	Ambulatory	Single one-on-one psychoeducational session based on the representation approach to patient education
Wells, 2003 ⁹⁸	RCT	64	Ambulatory	Pain education with a hotline and pain education with provider-initiated followup telephone calls
Wilkie, 2010 ⁸²	RCT	151	Ambulatory	Individualized pain coaching on self monitoring and reporting

Abbreviations: RCT = randomized controlled trial; CBT = cognitive behavioral therapy

* All studies conducted in populations of cancer patients, besides Fuchs-Lacelle and Kovach, which focused on advanced dementia patients.

** Articles are listed together when more than one article provided results on the same study.

Table 7. Outcomes for studies targeting pain

Author/Year	Pain	QOL	BPI*	BPI Measure Reported*
Anderson 2004 ¹⁰⁶	NS	NS	Y	Worst pain, pain interference
Aubin, 2006 ⁸⁶	S		Y	Average pain, worst pain
Borneman, 2008 ⁸³	NS		N	
Borneman, 2010 ⁹²	NS		N	
Dalton, 2004 ¹⁰⁴	NS	NS	Y	Worst, least, average, pain now, pain right now, pain Interference with walking, sleep, relationships, activity, composite severity score, composite interference score
Du Pen, 2000 ⁹¹	S		Y	Aggregate score of worst pain and usual pain
Fuchs-Lacelle, 2008 ⁸⁴	NS		N	
Given, 2002 ⁹⁵	NS		N	
Keefe, 2005 ¹⁰²	NS	NS	Y	Worst pain, usual pain
Kovach 2006 ⁸⁵	S		N	
Lovell, 2010 ⁸⁸	S	NS	Y	Average pain, worst pain, pain interference
Marinangeli, 2004 ⁸⁹	S	NS	N	
Miaskowski, 2004 ⁹³ and Miaskowski 2007 ⁹⁴	S	NS (except for one subscale)	Y	⁹³ Least pain, average pain, worst pain ⁹⁴ Total interference score, individual scores for activity, mood, walking, work, relations with others, sleep, enjoyment of life, sexual activity
Oldenmenger 2011 ⁹⁰	S		Y	Current pain, average pain, worst pain in past 24 hours; pain interference
Oliver, 2001 ⁹⁹ Kalauokalani, 2007 ¹⁰⁷	S		Y	Average pain
Syrjala, 2008 ⁹⁶	S		Y	Usual pain, worst pain, interference with function (overall)
van der Peet, 2004 ⁸⁷	S	NS	Y	Present pain
Ward, 2000 ⁸¹	NS	NS	Y	Worst pain, pain interference composite score
Ward, 2008 ¹⁰⁰	NS	NS	Y	BPI severity composite score, pain interference composite score
Wells, 2003 ⁹⁸	NS		Y	Worst pain, average pain, pain interference, pain relief
Wilkie, 2010 ⁸²	NS		N	

Abbreviations: S = significant; NS = not significant; BPI = Brief Pain Inventory

*Whether or not BPI was the measurement tool used for the pain outcome, and which aspect of the BPI measure was reported. These were assessed to determine whether the measurement tools used, and the aspects reported, were homogeneous enough across studies for quantitative synthesis of the literature. BPI was used in many studies, but different aspects were reported across studies, making quantitative synthesis impractical.

Table 8. BPI results for studies targeting pain

Author/year	N	Pain	Quality Of Life	Brief Pain Inventory (BPI)	BPI Measure Reported	Reporting Issues for Studies Using BPI With Positive Findings
Anderson 2004	97	NS	NS	Y	Worst pain, pain interference	2 week and 1 month post-intervention assessment, no confidence intervals (CIs)
Aubin, 2006	80	S		Y	Average pain, worst pain	2 week and 4 week post-intervention assessment
Borneman, 2008	46	NS				
Borneman, 2010	157	NS				
Dalton, 2004	127	NS	NS	Y	Worst, least, average, pain now, pain interference with walking, sleep, relationships, activity, composite severity score, composite interference score	Assessment immediately post-intervention, 1 month, and 6 months; no CIs
Du Pen, 2000	105	S		Y	Aggregate score of worst pain and average pain	1 month, between 2.5 and 4 month post-intervention assessment; no CIs
Fuchs-Lacelle, 2008	173	NS				
Given, 2002	113	NS				
Keefe, 2005	78	NS	NS	Y	Worst pain, average pain	Assessment approximately one week after intervention; standard deviations, no CIs
Kovach 2006	114	S				
Lovell, 2010	185	S	NS	Y	Average pain, worst pain, pain interference	Unclear whether reporting 2 week or 4 week measurement in results
Marinangeli, 2004	92	S	NS			
Miaskowski, 2004 and Miaskowski 2007*	174	S	NS (except for one subscale)	Y	Least pain, average pain, worst pain Total interference score, individual scores for activity, mood, walking, work, relations with others, sleep, enjoyment of life, sexual activity	No CIs
Oldenmenger 2011{#40373}	72	S		Y	Current pain, average pain, worst pain in past 24 hours; pain interference	2 week, 1 month and 2 month assessment following intervention; No CIs
Oliver, 2001 and Kalauokalani, 2007*	67	S		Y	Average pain	2 week post-intervention assessment
Syrjala, 2008	78	S		Y	Average pain, worst pain, interference with function (overall)	1 month, 3 month, and 6 month assessment post-intervention; No CIs

Table 8. BPI results for studies targeting pain (continued)

Author/Year	N	Pain	Quality Of Life	Brief Pain Inventory (BPI)	BPI Measure Reported	Reporting Issues for Studies Using BPI With Positive Findings
van der Peet, 2004	120	S	NS	Y	Present pain	4 week assessment post-intervention, no CIs
Ward, 2000	43	NS	NS	Y	Worst pain, pain interference composite score	1 and 2 month post intervention followup, no data on BPI
Ward, 2008	176	NS	NS	Y	BPI severity composite score, pain interference composite score	1 month and 2 month assessment post-intervention
Wells, 2003	64	NS		Y	Worst pain, average pain, pain interference, pain relief	1 month post-intervention followup, continued monthly followup for six months; no CIs
Wilkie, 2010	151	NS				

Table 9. Grading of the evidence on studies addressing pain (KQ1a and KQ2a)

Number of Studies; Subjects	Domains Pertaining to Strength of Evidence, by Key Outcomes				Strength of Evidence That the Intervention Improved Outcomes Compared With the Control Group
	Risk of bias:	Consistency	Directness for outcome	Precision; Study diversity	
Pain					Moderate SOE
18; 2176	RCT/ Medium	Consistent	Direct	Not applicable; Medium	Moderate
3; 313	Non-RCT/ Medium	Inconsistent	Direct	Not applicable: Medium	Low
Quality of Life					Low SOE
7; 1259	RCT/ Medium	Consistent (no effect)	Direct	Not applicable; Medium	Low

Distress

Key Points

There was a low strength of evidence for outcome of distress, based on 7 high- and medium-quality RCTs with consistent results finding no improvement with the intervention.

Study Characteristics

We found seven studies that met our inclusion criteria for interventions in patients with serious and advanced illness and focused on the target of distress. The seven studies were published between 2005–2010 and had sample sizes ranging from 28-1,134 patients. All seven studies were RCTs. Of the seven studies, four were based in ambulatory settings, two were home-based and one was a combination of home and ambulatory settings. Five studies were multicenter and two were single-center trials. Six studies were in cancer populations and one study focused on patients eligible for lung transplant. All compared the intervention to usual care, except for one intervention that measured three different methods of distress screening. Because of the small number of interventions included in this section, study characteristics are

described for each individual study listed below. (Table 10, Appendix E, Evidence Tables 1, 10 and 11).

Studies addressing distress were less diverse in design than studies addressing continuity and pain. All but one study received risk of bias assessment of low. The one study assessed as having a medium risk of bias differed from the others in that it was unclear how the study handled sequence generation and allocation concealment. (For details on how each individual study was assessed see Appendix E, Evidence Table 12).

Key Question 1. What is the effectiveness of health care and palliative care interventions for improving the quality of palliative care?

Key Question 1a. Specific Targets

See Figure 1, Framework, column 3, for a listing of targets.

Only two of the seven studies demonstrated a significantly significant difference between the intervention and control groups. One RCT¹⁰⁸ evaluated 1,134 outpatients with lung (549 patients) or breast cancer randomized to one of three online methods of distress screening--a minimal screening group assessed using a distress thermometer only, a full screening intervention group using the problem checklist and a cancer-oriented psychological screen for anxiety and depression with a personalized feedback report, and a triage intervention group using and the full screen and personalized phone triage with an offer of referral to relevant resources. In the patients with advanced disease (the lung cancer group), the study¹⁰⁸ reported no change in distress among patients in the distress thermometer-only group or full screening group. They did find that, after the intervention, the triage intervention group had a significant improvement in the primary outcome of distress and fewer patients over the distress cutoff (30.7 percent), compared to the minimal screening group at 51.3 percent ($p=0.001$). There were no significant improvements in depression or anxiety (Table 11, Appendix E. Evidence Table 13).

Another RCT¹⁰⁹ randomized 328 lung transplant candidates to receive telephone-based coping skills training. For 12 weeks, they received weekly supportive counseling and training in cognitive-behavioral coping skills and education on stress and health, using a standardized program and trained therapists. For the primary outcomes of depression and distress, the study found that both depression and distress reduction in the intervention group was greater than the control group (11.1 to 9.8 vs. 12.6 to 8.8, $p=0.003$ and 45.2 to 43.2 vs. 48.1 to 39.7, $p=0.035$, respectively). There were no significant differences in several measures of QOL (Table 11, Appendix E. Evidence Table 13).

The five negative studies were all patient-oriented trials in cancer populations. One study¹¹⁰ enrolled 271 caregivers of patients dying of cancer at home, providing them six visits by advisors to assess needs and provide advice and support. Another¹¹¹ provided coaching on self-care, stress reduction, and communication strategies to 106 patients. A physician received summary results for assessment and conducted a telephone followup one week later. Porter¹¹² enrolled 233 lung cancer patients to receive caregiver-assisted coping skills training. The study randomized patient and caregiver groups to receive either 14 telephone-based, caregiver-assisted coping skills training sessions or 14 telephone-based, caregiver-assisted education/support sessions. In a small study, Steel¹¹³ randomized 28 patients to receive an individually tailored psychosocial intervention. Patients chose from a list of concerns that were most distressing (symptoms, psychological, and end of life issues) and received strategies to treat each problem. The final study¹¹⁴ enrolled 106 caregivers to evaluate a psycho-educational intervention for family

members. Nurses delivered the intervention during two home visits and a phone call. Caregivers received a guidebook and audiotape on caregiver role, self-care and care of the dying (Table 11, Appendix E. Evidence Table 13).

Key Question 1b. Specific Settings

No studies addressing this target applied to this Key Question.

Key Question 2. What is the evidence for different quality improvement models for improving palliative care?

Key Question 2a. Different Types of Quality Improvement Interventions

Key Points

Six of the seven studies for distress were patient education and self-management-oriented interventions. Only one of these studies found a significant improvement with the intervention.

Key Question 2b. Different Models in Palliative Care: Integrative Compared With Consultative

This Key Question was not analyzed for this target.

Grading of the Evidence

For distress, all studies were RCTs, and for both the outcomes of distress and depression, the risk of bias was medium, evidence was inconsistent, the outcome was direct, and precision was not applicable. Study diversity was high for distress and moderate for depression, and strength of evidence was low. (Table 12).

Table 10. Study characteristics of studies addressing distress

Author/Year	Study Design	Sample Size	Setting	Intervention
Aranda, 2006 ¹¹¹	RCT	106 patients	Ambulatory	Coaching on self-care, stress reduction and communication
Blumenthal, 2006 ¹⁰⁹	RCT	328 patients	Home-based	Telephone-based coping skills
Carlson, 2010 ¹⁰⁸	RCT	1134 patients	Ambulatory	Psychological screen with personalized feedback
Hudson, 2005 ¹¹⁴	RCT	106 patients	Home-based	Guidebook on caregiver role and self-care
Porter, 2010 ¹¹²	RCT	233 patients	Ambulatory	Telephone-based coping skills, education and support
Steel, 2007 ¹¹³	RCT	28 patients	Ambulatory	Patient identification of distress symptoms
Walsh, 2007 ¹¹⁰	RCT	271 patients	Home-based/Ambulatory	Needs assessment, advice and support

Abbreviation: RCT = randomized controlled trial

Table 11. Outcomes for studies targeting distress

Author/Year	Outcomes		
	Distress	Depression	Anxiety
Aranda, 2006 ¹¹¹	NS		
Blumenthal, 2006 ¹⁰⁹	S	S	NS
Carlson, 2010 ¹⁰⁸	S	NS	NS
Hudson, 2005 ¹¹⁴	NS	NS	
Porter, 2010 ¹¹²	NS		
Steel, 2007 ¹¹³	NS	NS	
Walsh, 2007 ¹¹⁰	NS		

Abbreviations: S= significant; NS = not significant

Table 12. Grading of evidence for distress (KQ1a and KQ2a)

Number of Studies; Subjects	Domains Pertaining to Strength of Evidence, by Key Outcomes				Strength of Evidence That the Intervention Improved Outcomes Compared With The Control Group
	Risk of bias	Consistency	Directness for outcome	Precision; Diversity of comparisons	
Distress					Low SOE
7; 2206	RCT/Medium	Consistent (no effect)	Direct	Not applicable; Moderate	Low
Depression					Low SOE
4; 1596	RCT/Medium	Consistent (no effect)	Direct	Not applicable; Moderate	Low

Communication and Decisionmaking

Study Characteristics

The sample sizes of the 20 studies were in the range of 63-2,891 patients with 57 percent between 150-900 patients and a mean sample size of 526. In total, 13 out of the 20 studies were conducted in an intensive care unit (ICU) with one of these in a neonatal ICU.¹¹⁵ The remaining seven studies were conducted in non-ICU settings: one nursing home, two ambulatory and four hospital. Of all the identified 20 studies, 50 percent were carried out in multiple centers and 50 percent in single centers; nine of the 20 studies were RCTs comparing the results of patients receiving an intervention to those receiving usual care, and the remaining 11 studies were non-RCTs. Of the 11 non-RCTs, seven were pre-post prospective studies conducted in the same setting with different sets of patients (Table 13, Appendix E, Evidence Table 1).

All but one of the populations in these studies consisted of adults with a mean age between 40 and 87. Most of the studies included patients with mixed illnesses (n=15) while others included mixed cancer patients only (n=2), advanced dementia patients only (n=1), trauma patients only (n=1) and pediatric patients with very low birth-weight (n=1) (Table 13, Appendix E, Evidence Table 1). All studies compared the intervention to usual care, except for one study of a question prompt list where both groups were seen by palliative care.

The types of interventions were categorized into four groups (Table 13):

1. Family meetings with one or more of the patient's usual health providers, usually a physician, nurse, and/or social worker. These family meetings were information sharing

- and/or decisionmaking meetings with patients and families to improve communication, particularly around end-of-life issues. Eleven studies used this type of intervention.
2. Interdisciplinary palliative care teams. Four studies¹¹⁶⁻¹¹⁹ used this type of intervention, including a palliative care physician and nurse, hospital social worker and/or chaplain that met with the patient/family and usual care clinical team to address issues such as patient symptoms, diagnosis, prognosis, and goals of care. One of these interventions also focused on advance care planning.¹¹⁶
 3. Ethics consultations. Two studies^{120,121} examined the impact of ethics consultations, defined as the use of specialized help in identifying, analyzing, and resolving ethical problems that arise in the care of the patient to resolve conflicts about life-sustaining interventions.
 4. Physician-patient communication. Two studies were in this category. One study evaluated the use of a question prompt list for patients with advanced cancer receiving palliative care consultation to assist patients to ask questions about end-of-life issues and improve patient-physician communication around prognosis/ end-of-life care issues.¹²² For the other study,¹²³ physicians in the intervention group used a CD-ROM training program on communication skills that was tailored with examples from their own clinic visits.

The target of intervention for 13 studies (65 percent) was the interdisciplinary team.^{45,48,118-121,124-130} Three studies (16 percent) addressed psychosocial and spiritual support in palliative care,^{117,120,122} while two RCTs focused on ethical issues in palliative care.^{120,121} Fourteen studies (70 percent) targeted advanced care planning and decisionmaking on goals of care in end-of-life care^{45,48,115,119,124-133} (Table 13, Appendix E, Evidence Tables 14 and 15).

All the studies (100 percent) on interventions for communication used patient, family and/or caregiver education as a quality improvement element. Eighty-five percent of these studies included promotion of self-management as an element of quality improvement.^{45,48,115,117,118,120-122,124-126,128-133} Eleven studies (55 percent) used facilitated relay of clinical data to providers as a component of intervention,^{45,48,117-120,122,126,127,129,130} and only one used provider reminder system for quality improvement.¹¹⁹ Other quality improvement elements used in these studies include provider education (50 percent),^{48,115,119-121,123,125,127,131,132} coaching and collaborative skills training to implement quality improvement (40 percent),^{48,119-121,125,127,129,131} audit and feedback (25 percent),^{45,48,117,129,130} organizational change (10 percent),^{117,119} and patient and family reminders (5 percent).¹¹⁸ None of these studies used financial incentives, regulations or policy as a quality improvement element for interventions to improve communication and decisionmaking in palliative care (Table 13, Appendix E, Evidence Tables 14 and 15).

Risk-of-bias scores were low for seven studies and medium for the remainder. In general, risk of bias was medium for the RCTs (Appendix E, Evidence Table 16).

Key Question 1. What is the effectiveness of health care and palliative care interventions for improving the quality of palliative care?

Key Question 1a. Specific Targets

See Figure 1, Framework, column 3, for a listing of targets.

Key Points

There was a moderate strength of evidence for the indirect outcome of health care utilization, based on 6 medium-quality RCTs and 9 RCTs with consistent results (11 of 15 studies showed improvement with the intervention).

Patient and Family Satisfaction

Eight studies evaluated patient satisfaction.^{45,115,117,118,122,123,129,131} Five of these eight studies were RCTs and three were non-RCTs. Only one RCT (14 percent) showed a statistically significant improvement on patient satisfaction;¹¹⁷ it used interdisciplinary palliative care service as an intervention to address patient and family needs for information and decisionmaking on goals of care. The studies with no significant improvement on patient satisfaction mainly used standardized family meetings with a physician, nurse, or social worker (not a palliative care team) as an intervention to improve communication and decisionmaking. (Table 14, Appendix E, Evidence Table 17).

Three studies assessed family satisfaction; two RCTs^{131,133} including one¹³¹ with a large sample size (n= 1,133) showed no significant improvement in family satisfaction, and a non-RCT with a small sample size (n= 88) showed significant improvement with the intervention in family satisfaction¹²⁹ (Table 14, Appendix E, Evidence Table 17).

Health Care Utilization

We categorized studies that evaluated ICU length of stay, hospital length of stay, and/or use of advance directives, as evaluations of health care utilization. Six RCTs of medium quality evaluated health care utilization in terminally ill patients.^{117,118,120,121,131,132} Four of these six studies (66.7 percent) showed a statistically significant improvement with the intervention compared to the control group (e.g., reduced ICU length of stay).^{117,120,121,131} Nine non-RCTs evaluated health care utilization. Seven of these nine non-RCTs (77.7 percent) showed a statistically significant improvement with the intervention.^{45,119,124-128} The sample size, intervention type, targets of the intervention, or setting, did not explain the difference in the four studies that showed non-significant results (Table 14, Appendix E, Evidence Table 17).

Quality of Life

Two good-quality RCTs assessed the QOL of patients.^{117,118} They both showed no significant improvement on QOL of patients in the intervention and usual care groups. These two studies independently used the same type of intervention (palliative care consultation) among different sample populations in similar settings to improve provider-patient and family communication and decisionmaking in palliative care (Table 14, Appendix E, Evidence Table 17).

Symptom Control

Four studies evaluated symptom control of patients: three of these four were good-quality RCTs,^{117,118,132} and the last was a medium-quality non-RCT.¹²⁹ Only one of these four studies (25 percent), an RCT,¹³² showed a statistically significant improvement in symptom control. It also had the smallest sample size (n= 63) of all the studies (Table 14, Appendix E, Evidence Table 17).

Key Question 1b. Specific Settings

We found no studies in hospice, but did find one study in the nursing home setting for this target. In a 2000 study, Molloy et al¹³¹ conducted an RCT educating providers, patients, and

families about advance directives, measuring end-of-life outcomes. Although there was no significant impact of the intervention on satisfaction, there was an impact on the rate of hospitalizations and hospital length of stay (2.61 vs. 5.86 days, $p=0.01$) (Table 14, Appendix E, Evidence Table 17, Appendix F).

Key Question 2. What is the evidence for different quality improvement models for improving palliative care?

Key Question 2a. Different Types of Quality Improvement Interventions

This Key Question was not analyzed for this target.

Key Question 2b. Different Models in Palliative Care: Integrative Compared With Consultative

Key Points

Four of the eight (50 percent) integrative studies had a significant improvement with the intervention, compared to six of the eight (75 percent) consultative studies.

Eight interventions were integrative and four of the eight (50 percent) had a significant improvement in at least one key outcome in the intervention compared to the control group. In contrast, eight interventions were consultative in nature and six of the eight (75 percent) had a significant improvement with the intervention in at least one key outcome. The interventions from four studies were combined (included both integrative and consultative models). Interventions were highly diverse and the number of studies in each classification group was small (Table 14, Appendix E, Evidence Table 17).

Grading of the Evidence

All outcomes were direct except health care utilization, and precision was not applicable because of heterogenous outcomes and outcome reporting. For patient satisfaction, both RCTs and non-RCTs had medium risk of bias; evidence was consistent (no effect), and strength of evidence was low. For family satisfaction, evidence was inconsistent, and strength of evidence was low. For health care utilization, risk of bias was medium for both RCTs and non-RCTs, evidence was consistent for impact of improvement in outcomes with the intervention, and strength of evidence was moderate: overall 11 out of the 15 studies (73 percent) showed an improvement with the intervention for this outcome. For QOL, risk of bias was low for two non-RCTs, evidence was consistent (no improvement with the intervention in either study), and strength of evidence was low. For symptom control, risk of bias was low for three RCTs and medium for non-RCTs; evidence was consistent for the RCTs (no improvement with the intervention) and strength of evidence was low. Strength of evidence was the same across RCTs and non-RCTs (Table 15).

Table 13. Characteristics of studies addressing communication and decisionmaking

Author, Year	Study Design	Sample Size	Setting	Centers	Mean Age	Disease Population	Family Meeting	Physician-Patient Communication	Palliative Care Team	Ethics Consultation
Ahrens, 2003 ¹²⁷	Non-RCT	151	ICU	single	Adult	Mixed illnesses	Yes			
Campbell, 2003 ¹¹⁹	Non-RCT	81	ICU	Single	Adult	Mixed illnesses			Yes	
Clayton, 2007 ¹²²	RCT	174	Ambulatory	Multi-center	65	Mixed Cancer		Yes		
Cowan, 2003 ⁴⁵	Non-RCT	873	ICU	Multi-center	61	Mixed illnesses	Yes			
Gade, 2008 ¹¹⁷	RCT	517	Hospital	Multi-center	73.6	Mixed illnesses			Yes	
Hanks, 2002 ¹¹⁸	RCT	261	Hospital	Multi-center	68.4	Mixed illnesses			Yes	
Jacobsen, 2011 ¹²⁵	Non-RCT	899	Hospital	Single	62.9	Mixed illnesses				
Kaufert, 2008 ¹²⁹	Non-RCT	88	ICU	Single	Adult	Mixed illnesses	Yes			
Laurette, 2007 ¹³²	RCT	63	ICU	Multi-center	68-74	Mixed illnesses	Yes			
Lilly, 2000 ¹²⁶	Non-RCT	530	ICU	Single	58-60	Mixed illnesses	Yes			
Lilly, 2003 ¹²⁴	Non-RCT	2891	ICU	Single	59	Mixed illnesses	Yes			
Molloy, 2000 ¹³¹	RCT	1133	Nursing Homes	Multi-center	83.1	Mixed illnesses				
Mosenthal, 2008 ¹²⁸	Non-RCT	367	ICU	Single	40	Trauma	Yes			
Muir, 2010 ⁴⁸	Non-RCT	480	ICU	Multi-center	53-56	Mixed illnesses	Yes			
Norton, 2007 ¹³⁰	Non-RCT	191	ICU	Single	66.1	Mixed illnesses			Yes	
Penticuff, 2005 ¹³⁴	Non-RCT	154	NICU	Multi-center	VLBW	Pediatric	Yes			
Sampson, 2011 ¹³³	RCT	32	Hospital	single	87	Advanced Dementia			Yes	
Schneiderman, 2000 ¹²¹	RCT	70	ICU	Single	45.9-52.4	Mixed illnesses				Yes
Schneiderman, 2003 ¹²⁰	RCT	546	ICU	Multi-center	67.5	Mixed illnesses				Yes
Tulsky, 2011 ¹²³	RCT	264	Ambulatory	Multi-center	61	Mixed Cancer		Yes		

Abbreviations: VLBW = very low birth weights; ICU = intensive care unit; NICU = neonatal intensive care unit

Table 14. Outcomes of studies addressing communication and decisionmaking

Author, Year	Study Design	Sample Size	Risk of Bias	Patient Satisfaction	Family Satisfaction	Health Care Utilization	Quality of Life	Symptoms	Integrative v. Consultative
Ahrens, 2003 ¹²⁷	Non-RCT	151	Low			Significant			Combined
Campbell, 2003 ¹¹⁹	Non-RCT	81	Medium			Significant			Consultative
Clayton, 2007 ¹²²	RCT	174	Low	Not Significant					Integrative
Cowan, 2003 ⁴⁵	Non-RCT	873	Medium	Not Significant		Significant			Consultative
Gade, 2008 ¹¹⁷	RCT	517	Low	Significant		Significant	Not Significant	Not Significant	Consultative
Hanks, 2002 ¹¹⁸	RCT	261	Low	Not Significant		Not Significant	Not Significant	Not Significant	Consultative
Jacobsen, 2011 ¹²⁵	Non-RCT	899	Medium			Significant			Integrative
Kaufer, 2008 ¹²⁹	Non-RCT	88	Medium	Not Significant	Significant			Not Significant	Consultative
Laurette, 2007 ¹³²	RCT	63	Low			Not Significant		Significant	Combined
Lilly, 2000 ¹²⁶	Non-RCT	530	Medium			Significant			Integrative
Lilly, 2003 ¹²⁴	Non-RCT	2891	Medium			Significant			Integrative
Molloy, 2000 ¹³¹	RCT	1133	Medium	Not Significant	Not Significant	Significant			Integrative
Mosenthal, 2008 ¹²⁸	Non-RCT	367	Medium			Significant			Combined
Muir, 2010 ⁴⁸	Non-RCT	480	Medium			Not Significant			Integrative
Norton, 2007 ¹³⁰	Non-RCT	191	Medium			Not Significant			Consultative
Penticuff, 2005 ¹³⁴	Non-RCT	154	Medium	Not Significant					Integrative
Sampson, 2011 ¹³³	RCT	32	Medium		Not Significant				Combined
Schneiderman, 2000 ¹²¹	RCT	70	Medium			Significant			Consultative
Schneiderman, 2003 ¹²⁰	RCT	546	Low			Significant			Consultative
Tulsky, 2011 ¹²³	RCT	264	Low	Not significant					Integrative
				Patient Satisfaction	Family Satisfaction	Health care utilization	Quality of Life	Symptoms	
Number of studies addressing outcome				8	3	15	2	4	
Number with statistically significant impact				1	1	11	0	1	

Table 15. Evidence grading for studies addressing communication and decisionmaking (KQ1a and KQ2b)

Number of Studies; Subjects	Domains Pertaining to Strength of Evidence, by Key Outcomes				Strength of Evidence That the Intervention Improved Outcomes Compared With the Control Group
	Risk of bias:	Consistency	Directness for outcome	Precision	
Patient Satisfaction					Low SOE
5; 2349	RCT/ medium	Consistent (no effect)	Direct	Not applicable	Low
3;1115	Non-RCT/ medium	Consistent (no effect)	Direct	Not applicable	Low
Family satisfaction					Low SOE
2; 1165	RCT/ medium	Inconsistent	Direct	Not applicable	Low
1;88	Non-RCT/ medium	Not applicable	Direct	Not applicable	Insufficient
Health care utilization*					Moderate SOE
6; 2590	RCT/ medium	Consistent	Indirect	Not applicable	Moderate
9; 6463	Non-RCT/ medium	Consistent	Indirect	Not applicable	Moderate
QOL					Low SOE
2;778	RCT/ low	Consistent (no effect)	Direct	Not applicable	Low
0	Non-RCT/ not applicable	Not applicable	Direct	Not applicable	Not applicable
Symptom control					Low SOE
3; 841	RCT/ low	Consistent (no effect)	Direct	Not applicable	Low
1; 88	Non-RCT/ medium	Not applicable	Direct	Not applicable	Insufficient

* Intensive care unit or hospital length of stay, advance directive completion

Interventions With Multiple or Other Targets

Key Points

Low strength of evidence was found across outcomes, including improvement of quality of life and symptom relief, for interventions with multiple or other targets.

Study Characteristics

This section includes studies that met the inclusion criteria but mainly focused on multiple targets or, in a few cases, addressed a target outside the four key targets (e.g., timeliness of treatment). Given the diversity of studies, this section is organized differently than previous sections—by type of quality improvement intervention. These studies mostly fit a narrower definition of quality improvement and address the evidence specifically for these quality improvement types. The sample sizes of the 19 studies described in 21 articles were in the range of 53–822 patients (and one study addressing 644 clinical sites).¹³⁵ Ten studies were in the ambulatory setting, two in an ICU, two in the home setting, two in a nursing home, one in hospice, one in multiple sites, and one in another setting (palliative day-care center). Eleven were RCTs (Table 16, Appendix E, Evidence Tables 1, 18 and 19). Because this group of studies was so diverse, characteristics of each study are described separately rather than summarized for the entire section.

Risk of bias was low for four studies, medium for 14 studies, and high for one. In general, RCTs had low or medium risk of bias. Most studies did not report blinding, and some RCTs did not report details of randomization or allocation (Appendix E, Evidence Table 20).

Key Question 1. What is the effectiveness of health care and palliative care interventions for improving the quality of palliative care?

Key Question 1a. Specific Targets

See Figure 1, Framework, column 3, for a listing of targets.

This Key Question was not analyzed for these studies which focused on multiple or other targets.

Key Question 1b. Specific Settings

We found one study (described in two publications) in the hospice setting and two studies in nursing homes.

For hospice, one RCT^{136,137} randomized caregivers to the Creativity, Optimism, Planning, Expert (COPE) information intervention, compared to standard hospice care. The study found significant improvements with the intervention on caregiver QOL (estimate 0.096, $p=0.04$) and task burden (estimate 0.01, $p=0.04$), as well as patient distress (estimate 0.101, $p=0.009$) (Table 17, Appendix E, Evidence Table 21).

For nursing homes, one study addressed provider education and one included multiple quality improvement types. Keay¹³⁸ conducted a half-day physician education multicenter RCT that provided quality improvement suggestions to the medical directors. The study found statistically significant improvements in symptom control during dying for quality indicators related to terminal care in nursing homes (19 to 45 percent, $p<0.001$). Hanson et al¹³⁹

conducted a non-RCT including multiple quality improvement types in nine nursing homes. Post-intervention, there was a significant increase in hospice enrollment from 4 to 6.8 percent ($p=0.01$), and in the use of pain assessments (18 to 60 percent, $p<0.001$) and advance care planning discussions (4 to 17 percent, $p<0.001$). Use of pain interventions did not change (Table 17, Appendix E, Evidence Table 21, Appendix F).

Key Question 2. What is the evidence for different quality improvement models for improving palliative care?

Key Question 2a. Different Types of Quality Improvement Interventions

Physician/Other Provider Reminder Systems

We did not find any additional studies focusing on this quality improvement type other than those summarized in the target sections above (Table 17, Appendix E, Evidence Table 21).

Facilitated Relay of Clinical Data to Providers

We found six publications on five studies meeting our inclusion criteria focusing on relay of clinical information for quality improvement. The studies were published between 2000-2011 and had patient sample sizes ranging from 53-286. All five studies were RCTs conducted in ambulatory settings; four were single-centers treating in-patients with metastatic cancer, and one was multicenter, treating lung cancer patients (Table 17, Appendix E, Evidence Table 21).

Only one of the five studies demonstrated a significant improvement with the intervention on QOL or satisfaction. Velikova, 2004¹⁴⁰ conducted a three-arm RCT, randomizing patients to complete a touch-screen health-related QOL survey that provided feedback to physicians, to complete the QOL survey without feedback to physicians, or to not complete a survey. After three visits post-randomization, a higher number of symptoms were mentioned during the clinical encounter in the intervention group (where patients completed the survey that provided feedback to the physician) than in the other two control groups (Estimate Effect: 4.51; $p=0.03$). The intervention improved QOL when compared to the control group (Estimate Effect: 8.01, $p=0.006$). In an study reporting analysis of secondary outcomes of evaluations of care¹⁴¹, patients in the intervention group reported significantly higher ratings for communication ($p=0.03$) but not for two other subscales or for satisfaction with care (Table 17, Appendix E, Evidence Table 21).

Mills, 2009¹⁴² studied the use of a structured patient-held QOL diary at home weekly for 16 weeks; patients were encouraged to share it with their health care providers. There were no significant differences between the groups for the primary QOL measure or for satisfaction. However, there were some significantly worse secondary QOL outcomes in the intervention group compared to the control group. Most patients did not give feedback to their providers (Table 17, Appendix E, Evidence Table 21).

Detmar¹⁴³ used a QOL questionnaire among patients undergoing palliative chemotherapy at three consecutive visits to determine the effect on patient-physician communication. Ten physicians were enrolled in a randomized, crossover study to receive a graphic summary of responses to the questionnaire prior to consultation. After three visits, patients in the intervention group reported significantly greater communication on QOL issues with their physicians than

those in the control (Mean: 4.7 vs. 3.7; $p=0.01$), but there was no significant differences in secondary outcomes of QOL or patient satisfaction (Table 17, Appendix E, Evidence Table 21).

Two studies^{144,145} found no differences in any reported outcomes between their intervention and control groups. Rosenbloom, 2007¹⁴⁴ evaluated the improvement with QOL screening with physician interpretive assistance on QOL outcomes and satisfaction among patients with metastatic cancer. This three-arm study randomized 213 patients to complete a QOL survey with followup interview and discussion, complete a QOL survey without followup or receive usual care. After followup at three and six months, the study saw no significant improvement in QOL and satisfaction among the groups Taenzer, 2000,¹⁴⁵ evaluated the effect of a computerized screening on physician behavior and patient satisfaction. The study randomized 53 patients with lung cancer undergoing treatment to complete a computerized QOL survey prior to consultation that clinical staff reviewed. The study saw no significant differences in patient satisfaction or physician charting between the two groups (Table 17, Appendix E, Evidence Table 21).

Audit and Feedback

We identified two studies focusing on audit and feedback. Campion et al.¹³⁵ reported the evaluation of end-of-life outcome measures in the American Society for Clinical Oncology (ASCO) Quality Oncology Practice Initiative (QOPI) in 644 clinical sites. This voluntary initiative includes a twice-yearly data reporting and analysis cycle and offers participating practices extensive, site-specific, and benchmarking reports that describe the continuum of care. Sites reporting in multiple periods vs. sites reporting only in Fall 2010 had statistically significantly better performance on multiple quality measures, including all four measures for pain management, two of three dyspnea measures, and four of seven measures on hospice and palliative care discussions and referrals; there was no difference in chemotherapy use at the end of life. Jacobs et al.¹⁴⁶ conducted a non-RCT where physicians received three biannual palliative care reports on patients where death was likely, including patient/family satisfaction and reported symptom relief and timeliness of advance directive discussions. The study found no difference in quality of care on 10 items evaluated through chart reviews. Physicians may not have reviewed their reports, and feedback may have been too delayed (between 3 and 9 months after care) (Table 17, Appendix E, Evidence Table 21).

Provider Education

We identified one non-RCT addressing only this quality improvement type that met the inclusion criteria. Keay¹³⁸ conducted a half-day education seminar for five nursing homes and provided quality improvement suggestions targeting medical directors and physicians with the majority of patients. A before-after evaluation found statically significant improvements in symptom control during dying for quality indicators for terminal care for nursing homes (19 to 45 percent, $p<0.001$).

Patient/Caregiver Education and Self-Management

We identified six publications on five studies that met inclusion criteria and focused on this quality improvement type but addressed multiple targets and symptoms. Four of the studies^{136,147,148} focused on reducing symptom severity, one study¹⁴⁹ focused on maintaining QOL for patients with advanced cancer. These studies were published between 2005 and 2007 and had sample sizes ranging between 115 and 437. The patient populations in these studies had a cancer diagnosis. All studies were randomized, controlled trials. Two of the studies^{147,149} were

in ambulatory settings, one¹⁴⁸ in the home setting, one¹³⁶ in hospice, and one in multiple settings. Two¹⁵⁰ were multicenter studies while the others were single-center. All studies had a consultative approach (Table 17, Appendix E, Evidence Table 21).

One study¹⁴⁷ randomized 124 patients with stage III or stage IV cancer receiving chemotherapy to either standard of care or standard of care plus a cognitive behavioral intervention targeted to decrease severity of symptoms. Experienced oncology nurses delivered five contacts over an 8-week time period aimed at teaching problem-solving techniques to reduce symptom severity. The nurses contacted the patients in person for the first and last sessions, and held the second, third and fourth sessions via telephone. They held the sessions at two-week intervals. The study assessed symptom severity and depressive effect at baseline, 10 weeks, and 20 weeks. The study used The Center for Epidemiologic Studies-Depression Scale to measure depressive symptoms. Patients rated the severity of their symptoms using a 0-10 scale, with 0 representing symptom not present, and 10 representing as severe as it could possibly be. Patients in the intervention group had a mean symptom severity score of 19.1 at 10 weeks (SD=13.1) versus 27.7 (SD=18.9) for the control group. At 20 weeks patients in the intervention group had a mean symptom severity score of 22.1 (SD=15.2) versus 28.2 (SD=19.6) in the control group. Participating in the intervention proved a predictor of lower symptom severity at 20 weeks ($p=0.02$). The top two reasons for attrition were death (43 percent, $N=17$) and advancing disease (33 percent, $n=13$) (Table 17, Appendix E, Evidence Table 21).

The second study¹⁴⁸ randomized 437 patients with cancer undergoing chemotherapy to either nurse-assisted symptom management (NASM) or automated telephone symptom management (ATSM). The study compared the impact of a six-contact, 8-week ATSM intervention delivered through an automated system with a NASM intervention (which had previously been found to improve outcomes compared to standard care) delivered by experienced cancer nurses. The study looked at reducing the severity of 17 common symptoms experienced by patients receiving chemotherapy. The study¹⁴⁸ assessed severity of 17 symptoms scored by patients using a 0-10 scale (where 0 was no symptom and 10 was the worst severity possible at baseline), at each of the six intervention contacts and at 10 weeks. The study set a threshold at below four or four and higher. It used a Rasch analysis for the data collected at each of the six intervention contacts. The study found no significant differences between the NASM and the ATSM groups post intervention. This study noted a difference in symptom severity between lung and non-lung cancer patients and suggests this as an area for further study (Table 17, Appendix E, Evidence Table 21).

The third study^{136,137} randomized caregivers of hospice patients to the Creativity, Optimism, Planning, Expert (COPE) information intervention with three home visits and two interim calls to assist with symptom management, compared to standard hospice care. For the primary outcomes, which were caregiver outcomes,¹³⁷ the study found an impact on caregiver QOL (estimate 0.096, $p=0.04$) and task burden (estimate 0.01, $p=0.04$), as well as the burden of patient symptoms. For patient symptoms,¹³⁶ the study found no impact on dyspnea or pain, but did find an impact on distress (estimate 0.101, $p=0.009$) (Table 17, Appendix E, Evidence Table 21). The fourth study also used the COPE intervention for patient-caregiver dyads for advanced cancer patients participating in clinical trials, over three educational sessions. The study found statistically significant improvements in caregiver ($p=0.02$), but not patient, quality of life, but neither patients nor caregivers showed any change in problem-solving skills.¹⁵¹

The fifth study¹⁴⁹ randomized 115 advanced cancer patients to either eight structured multidisciplinary sessions or to standard of care. The eight structured sessions lasted for 90

minutes each and addressed the domains of QOL, including cognitive, physical, emotional, spiritual and social functioning. The participants in the intervention group received a manual reviewing material covered in the eight sessions. The study used the Spitzer QOL Uniscale for the primary outcome measure, overall QOL, and the Linear Analog Scale of Assessment of QOL for 12 secondary outcome measures. QOL was assessed at baseline, week four, week eight and week 27. The end of week four marked the end of the intervention in the study. While the results showed a significant difference between intervention and control groups for the primary outcome measure, overall QOL, at the week-four comparison ($P=0.047$), the results did not show any significant difference between the groups at weeks eight and 27. There was no significant difference found between the control group and intervention group in regards to secondary outcome measures except for spiritual wellbeing ($p=0.003$) at week four. Additional secondary outcome measures were assessed using the Symptom Distress Scale, Profile of Mood States-Short Form, and the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being, but none were significant in this study. Of note, this study cost \$2,000 for each participant, and recruitment was low: although the participants were all enrolled in radiation therapy and coming to the center daily for treatment, of 418 potential study participants asked to join the study, only 115 enrolled (Table 17, Appendix E, Evidence Table 21).

In summary, four of the five studies of interventions focusing on patient and caregiver education for multiple patient symptoms or QOL had statistically significant findings for at least one key outcome, although one was significant only at one of three time points (Table 17, Appendix E, Evidence Table 21).

Organizational Change

We identified one study focusing on organizational change. Holt¹⁵² conducted a before-after study of a rapid-response clinic for patients referred for palliative radiotherapy to reduce wait times and have patients seen same-day if possible. They found a statistically significant increase in single-fraction treatment (which is guideline-recommended care) (65 vs. 42 percent, $p=0.002$), and a statistically significant reduction in time-to-treatment (<24 hours) (74 vs. 27 percent, $p<0.001$) but found no improvement in waiting times for consultation (Table 17, Appendix E, Evidence Table 21).

Financial Incentives, Regulation, and Policy

We did not identify any additional studies for this quality improvement type outside of continuity of care (Table 17, Appendix E, Evidence Table 21).

Multiple Quality Improvement Types

We identified three studies that focused on multiple quality improvement types and multiple targets; two studies evaluated the same intervention, one in a non-RCT and the second in a multicenter RCT. Curtis et al.^{153,154} conducted the Integrating Palliative Care in the ICU study. The study included the quality improvement types clinician education, local champions, academic detailing, feedback to clinicians, and system support, in an integrative intervention with no consultative component. The non-RCT of the intervention found no significant impact on family-completed Quality of Dying and Death or satisfaction¹⁵³ However, the median length of stay in the ICU was significantly lower in the intervention group compared to the control group (3.85 vs. 3.06, $p=0.01$). In the multicenter RCT in 12 hospitals, there were no significant differences in any of these outcomes (Table 17, Appendix E, Evidence Table 21).¹⁵⁴

Hanson et al.¹³⁹ conducted a quality improvement non-RCT over a six month period that included multiple quality improvement types in nine nursing homes. The intervention used a plan-do-study-act structure with feedback of performance data at three time points. The quality improvement types studied included recruitment and training of palliative care leadership in each facility, in-depth education and technical assistance meetings for team members, as well as educational sessions for nursing staff. Post-intervention, there was a significant increase in hospice enrollment from 4 to 6.8 percent ($p=0.01$), and in the use of pain assessments (18 to 60 percent, $p<0.001$) and advance care planning discussions (4 to 17 percent, $p<0.001$); use of pain interventions did not change. The nursing homes were relatively diverse, and all volunteered to participate in this study (Table 17, Appendix E, Evidence Table 21).

Other

In this category, we identified two studies evaluating new clinical services in palliative care and addressing multiple targets. Goodwin et al.¹⁵⁵ found no significant impact on QOL in 173 United Kingdom patients at a palliative daycare center who received a variety of social, recreational, and therapeutic activities for five hours, one day a week, compared to usual palliative care. The needed sample size was not reached in this study and the outcome measures may not have effectively matched the goals of the intervention. Grande et al.¹⁵⁶ conducted a single-center RCT published in 2000 of hospital at home for palliative care; the intervention had an impact on only one of seven symptoms and no impact on psychosocial symptoms and support or the percentage who spent time at home in the last two weeks of life (Table 17, Appendix E, Evidence Table 21).

Key Question 2b. Different Models in Palliative Care: Integrative Compared With Consultative

This Key Question was not analyzed for this target.

Grading of the Evidence

Study diversity was high amongst these studies, and due to diversity of outcomes, precision was not applicable. All outcomes were direct, except quality of care (since this is not a directly patient-centered outcome), all had medium risk of bias for both RCTs and non-RCTs, and all had inconsistent data where applicable. For the outcome of QOL, there were six RCTs and two non-RCTs. For satisfaction, there were five RCTs and one non-RCT. For quality of care, there was one RCT and two non-RCTs. For patient symptoms, there were five RCTs and one non-RCT. For psychosocial support, there were two non-RCTs (Table 18). Strength of evidence was low overall, and the same for RCTs and non-RCTs

Table 16. Characteristics of studies addressing multiple or other targets

Targets	Author/Year	Study Design	Sample Size	Setting	Intervention
Facilitated relay of clinical data	Detmar, 2002 ¹⁴³	RCT	214	Ambulatory	Preconsultation QOL survey
	Mills, 2009 ¹⁴²	RCT	115	Ambulatory	Patient-held QOL diary
	Rosenbloom, 2007 ¹⁴⁴	RCT	213	Ambulatory	QOL survey with interpretive assistance
	Taenzer, 2000 ¹⁴⁵	RCT	53	Ambulatory	Preconsultation QOL survey
	Velikova, 2004 ¹⁴⁰ , Velikova, 2010 ¹⁴¹	RCT	286	Ambulatory	Preconsultation QOL survey
Audit and feedback	Campion, 2011 ¹³⁵	Non-RCT	644 sites	Ambulatory	Performance measurement program
	Jacobs, 2002 ¹⁴⁶	Non-RCT	194	Hospital	Evaluative feedback to individual physicians
Provider education	Keay, 2003 ¹³⁸	Non-RCT	176	Nursing home	Half-day physician education with audit and feedback
Patient/caregiver education and self-management	Sherwood, 2005 ¹⁴⁷	RCT	124	Ambulatory	Cognitive-behavioral intervention for symptoms
	Sikorskii, 2007 ¹⁴⁸	RCT	435	Home	Nurse-assisted symptom management
	McMillan, 2007 ¹³⁶ 2006 ¹³⁷	RCT	709	Hospice	Training family caregivers to assist with symptom management
	Meyers, 2011 ¹⁵¹	RCT	476	Ambulatory/home	Problem-solving with patient-caregiver dyads
	Rummans, 2006 ¹⁴⁹	RCT	115	Ambulatory	Structured multidisciplinary QOL intervention
Organizational change	Holt, 2010 ¹⁵²	Non-RCT	292	Ambulatory	Clinic providing more accessible, efficient palliative radiotherapy
Multiple quality improvement types	Curtis, 2008 ¹⁵³	Non-RCT	590	ICU	Education, local champions, feedback, system support
	Curtis, 2011 ¹⁵⁴	RCT	822	ICU	Same as above
	Hanson, 2005 ¹³⁹	Non-RCT	458	Nursing home	Plan-do-study-act with education, training, feedback, leadership
Other (new clinical services)	Goodwin, 2003 ¹⁵⁵	Non-RCT	173	Other	Palliative day care
	Grande, 2000 ¹⁵⁶	RCT	229	Home	Hospital at home for palliative care

Table 17. Outcomes of studies addressing multiple and other targets*

Target	Author, Year	Study Design	Sample Size	QOL	Satisfaction	Quality of Care	Patient symptoms	Caregiver QOL	Caregiver psychosocial support	Hospice Use	Health Care Use	Psycho-social Support	Symptoms
Facilitated relay of clinical data	Detmar, 2002 ¹⁴³	RCT	214	NS	NS								
	Mills, 2009 ¹⁴²	RCT	115	NS	NS								
	Rosenbloom, 2007 ¹⁴⁴	RCT	213	NS	NS								
	Taenzer, 2000 ¹⁴⁵	RCT	53		NS	NS							
	Velikova, 2004 ¹⁴⁰ , Velikova, 2010 ¹⁴¹	RCT	286	S	NS								
Audit and feedback	Campion, 2011 ¹³⁵	Non-RCT	644 sites			S (10/15 measures)							
	Jacobs, 2002 ¹⁴⁶	Non-RCT	194			NS (9/10 items)							
Provider education	Keay, 2003 ¹³⁸	Non-RCT	176			S							
Patient/caregiver education and self-management	Sherwood, 2005 ¹⁴⁷	RCT	124				S						
	Sikorskii, 2007 ¹⁴⁸	RCT	435				NS						
	McMillan, 2007 ¹³⁶ , 2006 ¹³⁷	RCT	709				NS pain, S distress	S	S				
	Meyers, 2011 ¹⁵¹	RCT	476	NS				S					
	Rummans, 2006 ¹⁴⁹	RCT	115	S			NS						
Organizational change	Holt, 2010 ¹⁵²	Non-RCT	292			S							

Table 17. Outcomes of studies addressing multiple and other targets* (continued)

Target	Author, Year	Study Design	Sample Size	QOL	Satisfaction	Quality of Care	Patient symptoms	Caregiver QOL	Caregiver psychosocial support	Hospice Use	Health-care use	Psycho-social Support	Symptoms
Multiple quality improvement types	Non-RCT	590	NS	NS						S			Non-RCT
	RCT	822	NS	NS						NS			RCT
	Non-RCT	458			S				S				Non-RCT
Other (new clinical services)	Non-RCT	173	NS (9/10 items)										Non-RCT
	RCT	229								NS	NS	NS (6/7 items)	RCT

* empty cells = not reported

Abbreviations: RCT = randomized controlled trial; NS = not significant; S = significant; QOL = quality of life

Table 18. Grading of studies in multiple or other targets (KQ2a)

Number of Studies; Subjects	Domains Pertaining to Strength of Evidence				Strength of Evidence That the Intervention Improved Outcomes Compared With the Control Group
	Risk of bias:	Consistency	Directness for outcome	Precision; Diversity of comparisons	
Quality of Life					Low SOE
7; 1300	RCT/medium	Inconsistent	Direct	Not applicable; High	Low
2; 763	Non-RCT/medium	Inconsistent	Direct	Not applicable; High	Low
Satisfaction					Low SOE
5; 881	RCT/ medium	Inconsistent	Direct	Not applicable; High	Low
1; 590	Non-RCT/medium	Not applicable	Direct	Not applicable	Low
Quality of Care					Low SOE
1; 53	RCT/ medium	Not applicable	Indirect	Not applicable	Low
3; >486*	Non-RCT/medium	Inconsistent	Indirect	Not applicable; High	Low
Patient Symptoms					Low SOE
5; 1612	RCT/ medium	Inconsistent	Direct	Not applicable; High	Low
1; 176	Non-RCT/medium	Not applicable	Direct	Not applicable	Low
Psychosocial Support					Low SOE
2; 938	Non-RCT/medium	Inconsistent	Direct	Not applicable; High	Low

*One study did not report # of patients—conducted in 644 sites

Discussion

Summary of Key Findings and Strength of Evidence

In summary, we found a significant number and wide variety of studies of interventions to improve health care and palliative care for patients with advanced and serious illness. Studies were highly heterogeneous across most targets for study interventions, quality, and outcomes, with many studies evaluating multiple outcomes. Many studies addressed a variety of different types of quality improvement types, particularly for the target of continuity, coordination and transitions. For this target, strength of evidence was moderate for the outcomes of patient and caregiver satisfaction, where four of six studies (67 percent) for patients and four of six studies (67 percent) for caregivers found a statistically significant improvement with the intervention, and low for other outcomes: three of nine studies (33 percent) found a statistically significant improvement for the outcome of quality of life and none found improvement for the outcome of overall symptoms. Only five of 16 studies (31 percent) of those that evaluated health care utilization as an outcome found a statistically significant effect in favor of the intervention. Studies that included patient-centered quality improvement types, such as education and self-management, had the strongest evidence of effectiveness on patient- and family-centered outcomes such as satisfaction and quality of life, compared to types such as organizational change. On the other hand, studies focusing on provider-focused interventions (e.g., education, reminders) were more likely to have an impact on the outcome of health care utilization than studies focusing on other quality improvement types, although these studies were mainly non-randomized clinical trials (RCTs).

Strength of evidence was moderate for the target and outcome of pain, where almost all of the 21 studies that we included focused on patient education and self-management: 10 studies (47 percent) found a statistically significant improvement of the intervention on pain outcomes compared to the control group. Patient/caregiver education and self-management encompassed most of the pain and distress studies: strength of evidence was moderate for pain, with approximately half of studies showing a significant improvement with the intervention.

Strength of evidence was low for distress, where only two of seven included studies (29 percent) found a statistically significant improvement with the intervention on the outcome of distress or depression – a detailed psychosocial screen in the cancer care setting with triage to appropriate services, and a support program for lung transplant candidates; no patient education/self-management programs in cancer patients found an impact.

For communication and decisionmaking, strength of evidence was moderate only for the outcome of health care utilization, where 11 of 15 studies (73 percent) that reported this outcome found a statistically significant impact in favor of the intervention, compared to only 22 percent of studies addressing patient or family satisfaction. Comparing the integrative and consultative models for quality improvement in this target, three-quarters of studies evaluating consultative interventions found a statistically significant improvement with the intervention on at least one key outcome, compared to half of the integrative interventions; no studies directly compared the two models.

In studies addressing other or multiple targets, patient/caregiver education/self-management and facilitated relay of clinical data to providers were the most common quality improvement types. Of four studies focusing on a broad variety of symptoms using patient education/self-management, three had statistically significant findings in favor of the intervention for symptom outcomes. Of studies addressing multiple targets and focusing on the quality improvement type

of facilitated relay of clinical data to providers, only one of five demonstrated a statistically significant improvement on either quality of life or satisfaction outcomes.

We found only two studies in hospices that met our inclusion criteria, both of which found a statistically significant improvement on at least one key outcome, and nine in nursing homes, seven of which demonstrated a significant improvement of the intervention on at least one outcome (with too few studies and diverse outcomes to make substantive conclusions about strength of evidence).

In this literature, we found that studies addressed a wide variety of illnesses, with many in mixed-cancer or mixed-illness populations. A number of studies also addressed specific cancer types, advanced pulmonary disease, and congestive heart failure, and one study focused on communication in extremely-low birthweight infants. We found a wide distribution of studies focusing on combinations of many different types of quality improvement interventions, as well as a variety of studies focusing on just one type of quality improvement intervention. Certain interventions, (e.g., self-management) received more attention than others (e.g., financial and regulatory). We also found a number of studies with multi-faceted interventions that used many quality improvement categories simultaneously.

The taxonomy of quality improvement types generally fit well, although application of the taxonomy to the field of palliative care did require some adjustments in definitions and types of interventions that were included in each category. For example, we found several studies addressing ordersets (usually for comfort care at the end of life), which we categorized as part of provider reminder interventions. We did add one additional category to the quality improvement type taxonomy, provider training in quality improvement methods, although few studies included this element. Across the different targets, the types of quality improvement differed as well, partly because of our inclusion criteria but also because of issues specific to the targets. Both pain and distress studies tended to be focused on patients or caregivers; few system-level distress studies exist, and system-level pain studies are also relatively rare and were not generally limited to patients with advanced disease.²⁵ Continuity interventions included a wide variety of quality improvement types.

In addition, the added dimension of different quality improvement models, separate from the taxonomy of quality improvement types, was important for analyzing quality improvement in this field. Consultation (addition of new services) was important for this area (palliative care consultation is an important element of quality improvement). We used the added dimension of integrative compared to consultative care to capture whether patients' usual providers or added providers were giving care. For the target of communication and decisionmaking, the dichotomy of integrative compared to consultative interventions fit better for study classification than the types of quality improvement.

In terms of the Institute of Medicine domains of quality intervention--efficacy, equity, safety, timeliness, patient-centeredness, and efficiency--studies generally focused on efficacy, patient-centeredness, and effectiveness. For efficacy, symptom outcomes were common, including pain and distress, as well as quality of life and outcomes addressing the causal pathway of interventions, such as pain barriers questionnaire for pain outcomes. We identified only one intervention focused on improving the efficiency and timeliness of care, in providing palliative radiotherapy. In terms of study design, results were generally consistent between RCTs and non-RCTs and between single-center and multi-center studies. In several instances, an initial non-RCT or single-center RCT was followed by a larger multicenter RCT, and results were generally consistent in the higher-quality studies.

Because of the diversity of the literature and outcomes, we were unable to draw conclusions about the influence of context (United States versus other), although studies of many effective interventions were conducted in the U.S. We also could not evaluate other context issues such as year of publication, or other organizational characteristics such as hospital size. A significant percentage of studies across the targets were multicenter studies. Descriptions of the context-sensitivity of interventions were minimal in the published studies. Time to followup was often short because of the severity of illness in included patient populations. Few studies evaluated followup at multiple time points, and for those who did, the results were often not consistent between time points (although sample sizes in these studies were often relatively small).

Details of the impact of implementation strategies were often absent or minimally reported, although a number of studies not evaluating effectiveness did report on implementation issues, such as challenges with recruitment and retention or low provider uptake of interventions. Many interventions did report on intermediate outcomes to help explain the causal pathway of the intervention, by using pain barriers questionnaires to assess the effectiveness of pain education interventions or measuring physician-provider communication about symptoms in studies evaluating facilitated relay of clinical data to providers.

Clinical Context and Applicability of Evidence for Decisionmaking

For the four key targets, we found moderate strength of evidence for at least one key outcome for all but distress. For continuity, although studies were relatively diverse, evidence supports the use of interventions with patient-centered components; strength of evidence was moderate for the outcome of satisfaction. Many studies measured multiple outcomes and results were not consistent across outcomes (e.g., significant results for health care utilization but not for patient satisfaction). However, we found several well-conducted, high- and medium-quality studies that found statistically significant improvements of the intervention compared to the control group across multiple patient-centered outcomes, such as an RCT of outpatient palliative care for lung cancer⁶⁴ and an RCT of facilitating hospice referrals for eligible nursing home patients.⁵⁴ These studies can serve as potential models for translation elsewhere. For pain, strength of evidence was moderate and almost entirely limited to cancer and patient-centered interventions. We found moderate strength of evidence that communication and decisionmaking interventions, including structured family meetings and palliative care and ethics consultations, can impact health care utilization. However, studies were mostly limited to the intensive care unit setting, and applicability to other settings is unclear. It is important to note that interventions were classified and analyzed by target, and therefore this report will be best used by first deciding what target is the focus, and then reviewing the strength of evidence for different outcomes, and reviewing the different intervention and quality improvement types that were used.

We found evidence for effectiveness of certain quality improvement strategies in palliative care, and consultative models were more likely to be effective than those of integrative ones. For pain, nurse-led patient and family caregiver-directed educational interventions demonstrated some improved outcomes; however, half of the included studies focusing on this quality improvement type showed no significant reduction in pain scores. Although only three studies out of the 19 included studies focused specifically on provider behavior (application of a pain management algorithm,⁹¹ the use of strong opioids as first-line therapy,⁸⁹ and a serial trial intervention to assess patients' unmet needs⁸⁵), all found significant improvements in patient

pain levels. Overall, due to the diversity of interventions included in this review, it is difficult to conclude what types of interventions are the most effective at reducing patient pain levels for patients with advanced and serious illness. Based on this review, no evidence exists about the effectiveness of other types of quality improvement, such as provider reminder systems or financial incentives, on improving patient pain outcomes. For distress, one study of psychosocial screening combined with triage to appropriate services showed evidence of effectiveness. For facilitated relay of clinical data, mainly use of quality of life questionnaires in outpatient oncology, evidence for effectiveness was weak. For other quality improvement types, and for the hospice setting, the number of studies was too small to draw conclusions. For the comparison between integrative, consultative, and combined models of palliative care, there were few combined studies. However, high- and medium-quality studies with strong evidence of effectiveness were found for both integrative and consultative models of care.

Few studies were found in the hospice and nursing home setting. Most studies focused on cancer patients, and only one study addressed pediatrics (in the neonatal intensive care unit), which limits applicability of this evidence to other populations.

Limitations of the Review Process

Although our focus on studies only meeting a definition of quality improvement, and our including or separately reporting results for patients with advanced or life-threatening illness, improves the applicability of the results, many types of studies were not included in this review, particularly those that did not focus on patients with very advanced or serious disease (only 96 studies were included in this review from a much larger literature). The definition that we developed, studies with a majority of patients with advanced or serious illness, was sometimes challenging to apply to studies because illness characteristics were not reported in detail, and also may have excluded some studies including some relevant populations. For example, we found that many studies, such as an evaluation of telecare management for pain and depression, included a majority of patients who were cancer survivors or had early-stage disease¹⁵⁷ or did not report the percentage of the population with advanced disease. In addition, although 25 percent of patients end their life in a nursing home, general nursing home populations would not have met the definition for “a majority of patients with advanced or serious illness” and studies in these populations were excluded.

This was also an issue for distress, where many interventions addressed general cancer populations or early-stage rather than advanced-stage disease. Few of these studies reported results for end-stage disease separately, so that we could abstract results; abstracting results for the whole population would have limited applicability, since patients’ needs at different stages of illness may vary markedly. Many of these areas where we provided a more focused review and excluded studies have been well-addressed in other systematic reviews in broader populations, such as pain management in nursing homes,³⁸ broader cancer pain interventions,²⁷ and studies addressing broader populations for communication in the intensive care unit.³⁴ For pain management, most included studies were patient- and caregiver-oriented interventions targeting this population specifically through study inclusion criteria and recruitment. This is due primarily to the fact that most institutional studies (e.g., in a hospital unit or entire nursing home) addressed broader populations or did not report results separately for advanced disease. Most advance care planning studies were excluded because they did not fit the definition of quality improvement (i.e., studies linked to the health care system and including an element of system

change); and most studies to improve rates of care planning were in populations that did not fit our definition, such as general primary care or nursing home populations.

Our focus on studies only with prospective components also excluded some relevant studies and quality improvement types. The inclusion criteria for patient-centered outcomes also excluded studies focusing only on intermediate or indirect outcomes such as quantity of communication or provider assessments of quality of care. These exclusion criteria limited the inclusion of most studies of regulatory or policy interventions, which usually were retrospective or did not include patient-centered outcomes, such as the Physicians Orders for Life-Sustaining Treatment in the United States, or the Gold Standards Framework in the United Kingdom. Although these exclusions did limit the scope of the review somewhat, they also improved the applicability by including only higher-quality studies with direct patient- or family caregiver-related outcomes. Due to our focus on clinical outcomes, we also did not address the issue of costs. The inclusion criteria for published, peer-reviewed evaluations also limited the inclusion of the experience evaluating interventions in areas less linked to academic medical centers and the research community, such as hospice and social work interventions,¹⁵⁸ and in areas that are less developed or where sample sizes are likely to be more limited, such as pediatrics.

We used a relatively broad definition of interventions to improve health care and quality improvement based on the original Closing the Quality Gap report, including studies conducted within or linked with the health care system and that have at least some element of system change. Palliative care consultation interventions, and interventions focusing on patient education and self-management, were included as part of this definition. Although these may not always be considered as quality improvement studies, they were included here because they are important methods for improving quality of care in patients with advanced and serious illness, particularly for pain management. Due to the diversity in the types of studies and the need to use one method for assessment of study quality across all studies, we used a risk of bias assessment tool for randomized trials, which did not capture many issues of methodologic quality within non-randomized quality improvement studies.

Finally, our focus on specific targets may have excluded some relevant studies, although we did include a variety of targets in the section on studies focusing on quality improvement. Included studies addressed a variety of targets, ranging from spirituality to timeliness and efficiency of care, with studies across all settings and in a variety of populations. Despite this focus, studies were still very heterogeneous, and even descriptive synthesis across such different studies has limitations.

Strengths and Limitations of the Literature

Although we identified a few high- and medium-quality studies with consistent findings within studies across outcomes, findings were often inconsistent among outcomes within the studies (e.g, statistically significant findings for health care utilization but not for satisfaction or symptoms) and many studies were of low quality or had methodological issues.^{54,64} RCTs are important in this field, and many of the highest-quality studies were RCTs, but since RCTs are often challenging or may not be the most appropriate study design for quality improvement interventions requiring institutional change, including the non-RCT literature was also important for this review. Common quality issues included small sample sizes, often due to insufficient recruitment, and lack of power for adequate statistical analysis. Even in many studies with adequate sample sizes, rates of recruitment were often low, reflecting the difficulty of conducting research in patients with advanced disease. Attrition was also a common issue, with a significant

percentage of patients dying before the followup assessment or being unable to complete the assessment, even with short followup times for many studies (one month or less); studies with multiple points of followup often had insufficient sample sizes for later evaluations or found inconsistent results across time points.

Because of the diversity of interventions, outcomes, and reporting in the included studies, we judged that quantitative synthesis was not appropriate for any of the targets. Even for the target of pain (where all included studies evaluated pain as an outcome and 67 percent of the studies used the BPI to measure and report pain), due to the differential reporting (with concern for selective outcome reporting) of the BPI components (e.g. average pain, worst pain) and infrequent reporting of confidence intervals, as well as diversity of study interventions and populations, we judged that quantitative synthesis was not appropriate. We adapted the approach of quantifying the number of studies with statistically significant improvement with the intervention for each key outcome across studies that was used in most previous systematic reviews of this literature.

Many studies included outcomes not designed for advanced disease or end-of-life populations, which may have limited the effectiveness of evaluating the impact of interventions. Studies often reported many outcomes and did not designate primary outcomes, making interpretation of results difficult and diluting the impact of study outcomes (e.g., reporting on a long list of outcomes rather than focusing on those most likely to be impacted by the intervention). For example, no interventions in the target of continuity found an impact on overall symptom scores, although this was reported as an outcome for a significant percentage of studies. In addition, evidence for different outcomes were often inconsistent within interventions and targets. For example, for continuity, statistically significant differences were twice as common for patient satisfaction as for quality of life, a finding consistent with systematic reviews evaluating the pre-2000 studies in this field.¹⁵ Three of four studies that evaluated caregiver satisfaction showed a significant effect on this outcome, but none found an effect on caregiver burden, not even within the same study.

These findings could also be due to limitations in outcome measures or to the modifiability of some outcomes in patients with advanced disease. For example, although satisfaction, or reports of patient/caregiver experience, is an important metric that can integrate patient/caregiver experiences of health care, it is also challenging to measure in patients with advanced and serious illness. It is usually measured retrospectively, so previous care, grief, and suffering all influence ratings. Studies also used a variety of tools, many of which were not specifically developed for end-of-life populations. Finally, many studies in continuity and communication focused on the indirect outcome of health care utilization. While this outcome is important and clearly modifiable by interventions, these studies often did not measure or did not show similar effectiveness for patient-centered outcomes.

Finally, we identified a number of limitations in the reporting of studies, which made interpretation difficult in general and for the purposes of this review. Studies often did not clearly report study design or details on the intervention. Although we only included studies with comparison groups, many studies focused on differences within the intervention group in the reporting of outcomes, not the comparison of interest. Studies often did not report effect size or complete results, which did not allow for estimation of the magnitude of effect. Studies often did not report the percentage of patients with advanced disease, and few separated out outcomes in palliative care compared to other populations. Descriptions of interventions were often limited, difficult to interpret, and challenging to translate into the quality improvement types. Few studies

identified theory or logic models; interventions often had not been well-evaluated in pilot studies identifying the most appropriate steps and outcomes, and often were not clearly developed based on existing literature. RCTs often did not report key elements, such as blinding or allocation, which lowered scores on risk of bias. Finally, studies often did not describe areas of context which might be helpful for understanding the strengths and limitations of settings and whether interventions could be replicated, such as local support for quality improvement, involvement of leadership, and funding and support for sustainability.

Future Research

We identified several key areas for future research. Development of measurement instruments specific for this special population has improved since earlier systematic reviews⁸ in some domains, such as quality of life and satisfaction, and we did find moderate strength of evidence for satisfaction for the target of continuity and a few key studies found effectiveness for quality of life. However, the lack of overall effectiveness results, particularly for quality of life, indicates that further development of measurement instruments for some outcomes may be warranted. Well-developed instruments may still be lacking in some key areas, such as caregiver burden. In addition, few studies evaluated caregiver burden as an outcome; this is a critical area for seriously ill patients that requires further research. For areas where instruments are well-developed, such as pain, standards for outcome measures and for how they are reported would help future attempts to compare and synthesize the literature. In addition, similar outcomes were often used across targets but not necessarily customized to those targets; further research could better define how to best tailor an outcome such as satisfaction to a target or intervention type, or better understand interactions between different types of outcomes commonly used together such as quality of life and satisfaction.

We identified few published studies in the hospice setting, pediatric populations, or addressing the target of distress in this population, or any studies focusing on diverse populations or reducing disparities in outcomes, areas where there is significant need but challenges in developing and evaluating quality improvement interventions. Examples of disparities in end-of-life care that should be addressed include lower ratings by families of black and Hispanic patients on the quality of hospice care in the domains of emotional support, communication, and honoring patients' preferences. Although significant effort has focused on quality improvement in hospices in recent years, hospices have traditionally been relatively separated from researchers and often independent of academic connections, leading to the lack of published research. Few studies focused on specific non-cancer populations, such as patients with heart failure.

Particularly in some areas, there were few studies on specific types of quality improvement. Pain and distress management studies included mainly patient-centered intervention types. Few studies evaluated regulatory or policy interventions using patient-centered outcomes, few studies used quality improvement methodological approaches such as collaboratives, Plan-Do-Study-Act cycles, and audit and feedback, and few studies evaluated care across settings. No studies compared consultative to integrative intervention approaches. Finally, we identified several high- and medium quality studies using specific types of interventions with significant results across several outcomes, that would benefit from replication, evaluations of dissemination, methods of implementation, and effectiveness in different settings.^{54,64}

Conclusions

In conclusion, we found the most consistent evidence in a large number of studies, including several high- and medium-quality studies, for the effectiveness of interventions targeting continuity for the outcome of patient satisfaction; targeting pain using patient-centered interventions; targeting communication and decisionmaking on health care utilization outcomes in the intensive care unit setting. A quality improvement taxonomy fit relatively well in this field of research with some modifications, including the addition of the integrative-consultative model framework for the target of communication and decisionmaking. The evidence has multiple gaps, including studies in illnesses other than cancer for symptom management; pediatric populations and hospice settings; and addressing diverse populations and disparities in care. Methods to achieve adequate retention and recruitment, and appropriate targeting of outcome measures to interventions and development and selection of the most appropriate measurement tools, are also needed to maximize the value of these studies. Finally, studies evaluating the impact of policy changes on patient outcomes are needed. This review provides a basis for researchers to understand which study methods, quality improvement types, and elements of interventions are best supported by current evidence, and for clinicians, quality improvement staff, and policymakers to conclude how best to target evidence-based efforts to improve the quality of care for patients with advanced and serious illness. Importantly, some key issues of health care for the seriously ill and dying, such as care across settings and existential, psychosocial, and caregiving issues are challenging to address in this type of research. More coordinated initiatives, across multiple settings and providers and following patient populations over longer periods of time, will be needed to better understand how best to improve care for patients with advanced and serious illness.

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Appendix A. Acronyms

Acronym	Definition
RCT	Randomized Controlled Trial
QOL	Quality of Life
KQ	Key Question
BPI	Brief Pain Inventory
POLST	Physicians Orders for Life Sustaining Treatment
EPC	Evidence-based Practice Center
COPD	Chronic Obstructive Pulmonary Disease
ROB	Risk of Bias
AHRQ	Agency for Healthcare Research and Quality
CQG	Closing The Quality Gap

Appendix B. Detailed Search Strategies

Appendix Table B1. General search strings

				Apr 2011 through Dec 2011
PubMed	((("end of life"[tiab] OR "palliative care"[mh] OR "palliative care"[tiab] OR "hospice care"[mh] OR "hospice care"[tiab] OR "supportive care"[tiab] OR "terminally ill"[tiab] OR "terminal care"[tiab]) AND ("quality improvement"[mh] OR "quality improvement"[tiab] OR "quality assurance, health care"[mh] OR "quality assurance"[tiab] OR "continuity of patient care"[mh] OR "patient care planning"[mh] OR "patient care planning"[tiab] OR consult[tiab] OR "systematic measurement"[tiab] OR "systematic assessment"[tiab])) NOT (editorial[pt] OR comment[pt]))	3419	Limited to 2000-2011	222
PsycINFO	(End of life OR palliative care OR hospice care OR supportive care OR terminally ill OR terminal care) AND (Quality improvement OR quality assurance OR continuity of patient care OR patient care planning OR consult OR systematic measurement) from 2000 to 2011	170		23
CINAHL	(End of life OR palliative care OR hospice care OR supportive care OR terminally ill OR terminal care) AND (Quality improvement OR quality assurance OR continuity of patient care OR patient care planning OR consult OR systematic measurement) from 2000 to 2011	1020		73
Cochrane				
1	Palliative care OR Palliative care MeSH	1592		
2	Hospice care OR Hospice care MeSH	154		
3	Quality assurance, health care MeSH	750		
4	Continuity of patient care MeSH	437		
5	Patient care planning OR patient care planning MeSH	408		
6	End of life OR supportive care OR terminally ill OR terminal care	4532		
7	#1 OR #2 OR #6	5864		
8	Quality assurance OR quality assurance, health care MeSH	988		
9	Patient care planning OR patient care planning MeSH	1680		
10	Quality improvement OR (quality assurance, health care MeSH OR quality assurance) OR continuity of patient care MeSH OR (patient care planning OR patient care planning MeSH) OR consult OR systematic measurement OR systematic assessment	12296		
11	#7 AND #10	1209		
12	#11 from 2000 to 2011	989		71
DARE	(End of life OR palliative care OR hospice care OR supportive care OR terminally ill OR terminal care) AND (Quality improvement OR quality assurance OR continuity of patient care OR patient care planning OR consult OR systematic measurement) from 2000 to 2011	42919420530		0

Appendix Table B2. Cancer management and pain search strings

				Apr 2011 through Dec 2011
PubMed	((Cancer[tiab] AND care[tiab]) AND (communication[mh] OR communication[tiab] OR psychosocial[tiab] OR distress[tiab] OR (pain[tiab] AND management[tiab]))) NOT (editorial[pt] OR comment[pt])	4536	Limited to 2000-2011	623
PsycInfo	(Cancer AND Care) AND Communication OR psychosocial OR distress OR (Pain AND management) from 2000 to 2011	1059		186
CINAHL				
1	Cancer AND care	83460		
2	Communication OR psychosocial OR distress	234643		
3	Pain AND management	51896		
4	S2 OR S3	279667		
5	S1 AND S4	18212		
6	S1 AND S4 from 2000 to 2011	2251		402
Cochrane				
1	Cancer AND care	4880		
2	Communication MeSH	1002		
3	(Cancer AND care) AND (Communication)	63		
4	Communication	4739		
5	(Cancer AND care) AND (Communication MeSH OR Communication tiab)	182		
6	Psychosocial OR distress	8672		
7	Pain MeSH	8539		
8	Pain	51077		
9	Management	29126		
10	(Cancer AND care) AND (Communication MeSH OR Communication tiab OR psychosocial OR distress OR ((pain MeSH OR pain tiab) AND management))	601		
11	(Cancer AND care) AND (Communication MeSH OR Communication tiab OR psychosocial OR distress OR ((pain MeSH OR pain tiab) AND management)) from 2000 to 2011	454		330
DARE	Cancer AND care AND (communication OR psychosocial OR distress OR (pain AND management)) from 2000-2011	1891076121		3

Appendix Table B.3. Nursing home and care planning pain search strings


				Apr 2011 through Dec 2011
PubMed	("nursing homes"[mh] OR "nursing homes"[tiab] OR "nursing home"[tiab]) AND ("patient care planning"[mh] OR "patient care planning"[tiab] OR (pain[tiab] AND management[tiab])) NOT (editorial[pt] OR comment[pt])	653	Limited to 2000-2011	41
PsycINFO	(Nursing homes OR nursing home) AND patient care planning OR (pain and management) from 2000-2011	149		0
CINAHL	(Nursing homes OR nursing home) AND patient care planning OR (pain and management) from 2000-2011	520		0
Cochrane				
1	Nursing homes MeSH	855		
2	Patient care planning MeSH	408		
3	Nursing homes OR nursing home OR nursing homes MeSH	3070		
4	Patient care planning OR patient care planning MeSH	1680		
5	Pain and management	4507		
6	#3 AND (#4 OR #5)	172		1
DARE	(Nursing homes OR nursing home) AND patient care planning OR (pain and management) from 2000-2011	100757234986		0

Appendix C. Screening Forms

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Refid: 12, Skateboards: Are they really perilous? A retrospective study from a district hospital.

Rehnam U, Yesupalan RS, Ginha A.

BACKGROUND: Skateboarding has been a popular sport among teenagers even with its attendant associated risks. The literature is packed with articles regarding the perils of skateboards, is the skateboard as dangerous as has been portrayed?

METHODS: This was a retrospective study conducted over a 5 year period. All skateboard related injuries seen in the Orthopaedic unit were identified and data collated on patient demographics, mechanism & location of injury, annual incidence, type of injury, treatment needed including hospitalisation.

RESULTS: We encountered 50 patients with skateboard related injuries. Most patients were males and under the age of 15. The annual incidence has remained low at about 10. The upper limb was predominantly involved with most injuries being fractures. Most injuries occurred during summer. The commonest treatment modality was plaster immobilisation. The distal radius was the commonest bone to be fractured. There were no head & neck injuries, open fractures or injuries requiring surgical intervention.

CONCLUSION: Despite its negative image among the medical fraternity, the skateboard does not appear to be a dangerous sport with a low incidence and injuries encountered being not severe. Skateboarding should be restricted to supervised skateboard parks and skateboarders should wear protective gear. These measures would reduce the number of skateboarders injured in motor vehicle collisions, reduce the personal injuries among skateboarders, and reduce the number of pedestrians injured in collisions with skateboarders.

Subtotal Form and go to or Skip to Next

KEY QUESTIONS
1. What is the evidence for the effectiveness of quality improvement interventions for key targets and settings relevant to palliative and end-of-life care?
a) Specific targets: What is the effectiveness for processes and outcomes for pain, communication, continuity, coordination, and transitions; and patient and family distress, in palliative and end-of-life populations?
b) Specific settings: What is the effectiveness for quality improvement interventions in any domain within hospice programs and in nursing homes?
2. What is the evidence for different quality improvement models for improving palliative and end-of-life care in the domains of pain and communication?
a) What is the evidence for different types of quality improvement interventions?
b) What is the evidence for different models in palliative care: structural, integrative, compared with consultative?
3. Does this apply to any of the key questions?

☐ No (Identify "exclusion criteria") ☒ Yes

3. Inclusion
☐ Systematic review (a literature review focused on a research question that tries to identify, appraise, select and synthesize all high quality research evidence relevant to that question.)
☐ Other accepted study design
[Clear Response](#)
☐ Unclear: no abstract, or cannot determine eligibility from abstract alone

4. Comment

Framework: <https://systematic-review.net/Generic/getAttachment.php?id=1>

EXCLUDE:
• If the study is evaluating an INTERVENTION that is clearly a THERAPY - such as art therapy or cognitive behavioral therapy, or a support group - as a therapy in one group of patients compared to another, it is not a QI intervention but a therapeutic intervention.
Some of the studies do get tricky, if it is trying to integrate more psychosocial support into health care, or if there's some to be a patient education/reminder/d data collection component (such as distress screening), we may need to look at the full article to sort out if this is a QI or therapy intervention. If you're not sure, just mark as "unclear" - see below where I have tailored the types of QI interventions somewhat to this field - will need to continue to work on this
• Studies on SCREENING, PREVENTION, or CANCER CONTROL
• QUALITATIVE studies
• CHRONIC NON-CANCER pain
• FOCUS GROUPS and usually SURVEY, w/ p if there is no intervention
• Advanced directives are planning intervention but not in a palliative care population

INCLUDE:
• Studies addressing lung, ovarian, hepatic or pancreatic cancers are generally addressing end-of-life or palliative care
• ADVANCE CARE planning addressing palliative and end-of-life care
• SYSTEMATIC REVIEWS: only include #1 and/or #2 if they title "systematic review" in the abstract
• SYMPTOM SCREENING, SYSTEMATIC ASSESSMENT are QI
• "PHARMACOLOGICAL" and "PSYCHOEDUCATIONAL" and be QI - should usually include; could be patient education, which is QI (include if it appears that there's a patient education component)
• QUANTITATIVE results
• Studies MUST have a control group to be an included intervention. A study body in a population (same group of patients) is NOT included (e.g., measuring pain in a group of patients before and after a pain education intervention) the only pre post studies are where the patients are different pre and post (not an intervention in a hospital)
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Refid: 12, Skateboards: Are they really perilous? A retrospective study from a district hospital.

Rethnam U, Yesupalan RS, Sinha A.

BACKGROUND: Skateboarding has been a popular sport among teenagers even with its attendant associated risks. The literature is packed with articles regarding the perils of skateboards. Is the skateboard as dangerous as has been portrayed?

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1. Does this apply to any of the key questions?

- ☒ No (identify "exclusion criteria") ☐ Yes
- ☐ Unclear: no abstract, or cannot determine eligibility from abstract alone

2. Exclusion Criteria (choose ONE) Definitions

- ☐ Not a study about quality improvement (see definition)
- ☐ Does not address a palliative care intervention or population
- ☐ Does not include patient- and family-centered outcomes in the results (see definition)
- ☐ Not an included study design (see definition)
- ☐ Other

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 ☐ Yes
☐ Unclear: no abstract, or cannot determine eligibility from abstract alone

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☐ Does not address a palliative care intervention or population
☐ Does not include patient- and family-centered outcomes in the results (see definition)
☐ Not an included study design (see definition)
☐ Other


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3. Inclusion

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☐ Other accepted study design

Clear Response

☐ Non-English language

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KEY QUESTIONS

1. What is the evidence for the effectiveness of quality improvement interventions for key targets and settings relevant to palliative and end-of-life care?
 - a) Specific targets: What is the effectiveness for processes and outcomes for pain; communication; continuity, coordination, and transitions; and patient and family distress, in palliative and end-of-life populations?
 - b) Specific settings: What is the effectiveness for quality improvement interventions in any domain within hospice programs and in nursing homes?
2. What is the evidence for different quality improvement models for improving palliative and end-of-life care in the domains of pain and communication?
 - a) What is the evidence for different types of quality improvement interventions?
 - b) What is the evidence for different models in palliative care: structural, integrative, compared with consultative?

1. Does this apply to any of the key questions?

☐ No (identify "exclusion criteria") ☒ Yes

3. Inclusion

- ☐ Systematic review (a literature review focused on a research question that tries to identify, appraise, select and synthesize all high quality research evidence relevant to that question.)
- ☐ Other accepted study design

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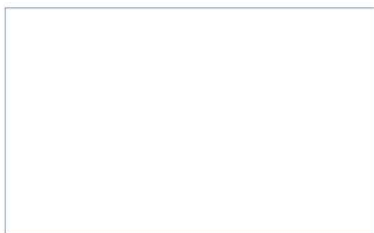
☒ No (identify "exclusion criteria") ☐ Yes ☐ Non-English language

2. Exclusion Criteria (choose ONE) [Definitions](#)

- ☐ Not a study about quality improvement (see definition)
- ☐ Does not address a palliative care intervention or population
- ☐ Does not include patient- and family-centered outcomes in the results (see definition)
- ☐ Not an included study design (see definition)
- ☐ Other

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5. Comment



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EXCLUDE:

- If the study is evaluating an INTERVENTION that is clearly a THERAPY - such as art therapy or cognitive-behavioral therapy, or a support group - as a therapy in one group of patients compared to another, it is **not a QI intervention** but a therapeutic intervention.
Some of these studies do get tricky, if it is trying to integrate more psychosocial support into health care, or if there seems to be a patient education/ reminder/ data collection component (such as distress screening), **we may need to look at the full article to sort out if this is a QI or therapy intervention**. If you're not sure, just mark as "unclear" - see below where I have tailored the types of QI interventions somewhat to this field - will need to continue to work on this
- Studies on SCREENING, PREVENTION, or CANCER CONTROL
- QUALITATIVE studies
- CHRONIC NON-CANCER PAIN
- FOCUS GROUPS and usually SURVEY, esp if there is no intervention
- Advanced directive/care planning intervention but **not in a palliative care population**

INCLUDE:

- Studies addressing lung, ovarian, hepatic or pancreatic cancers are generally addressing end-of-life or palliative care
- ADVANCE CARE planning addressing palliative and end-of-life care
- SYSTEMATIC REVIEWS: only include if they 1) address QI, and 2) if they state "systematic review" in the abstract
- SYMPTOM SCREENING, SYSTEMATIC ASSESSMENT are QI
- "NONPHARMACOLOGICAL" and "PSYCHOEDUCATIONAL" **can be QI** - should usually include, could be patient education, which is QI (include if it appears that there's a patient education component)
- QUANTITATIVE results
- Studies MUST have a control group to be an included intervention. A cohort study in a population (same group of patients) is NOT included (e.g., measuring pain in a group of patients before and after a pain education intervention); the only pre-post studies are where the patients are different pre and post (such as an intervention in a hospital).

NOTES:

QI intervention must occur within or affect care within the healthcare system.
Educational interventions must be linked to the aspect of care.

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Appendix D. Excluded Articles

Does Not Address a Palliative Care Intervention or Population

A Nurse Delivered Management Programme for Depression in People With Cancer Reduces Depressive Symptoms Compared With Usual Care.. Evidence-Based Mental Health 200902:9

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Appendix E. Evidence Tables

Evidence Table 1. Population and study characteristics of all included studies

Author, year	Population	Disease	Setting(s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Ahrens et al, 2003 ¹	Adult	Mixed	ICU	Single center	Controlled trial	Specific defined roles and EOL communication by physician & clinical nurse specialists	Whenever a certain ICU attending was on service, a clinical nurse specialist trained palliative care saw patients/families daily were involved to ensure optimal communication.
Aiken, 2006 ²	Adult, 69	COPD, CHF	Home care	Multicenter, 7 organizations	RCT, 6 month	Case management and coordinated care	Home-based case management provided by registered nurse case-managers, in coordination with patients' existing medical care. Program foci included disease and symptom management, patient self-management and knowledge of illness-related resources, preparation for end-of life, physical and mental functioning, utilization of medical services
Anderson, 2004 ³	adult	cancer	ambulatory	multi-center (6 onc clinics)	RCT	Education- video and booklet combination	Education specific to patient race/gender, highlighting misconceptions for pain relief, and how to talk to their provider about pain experience, followed by a 30-minute nurse-led meeting following the video administration, and one follow up call within three days.
Aranda, 2006 ⁴	Adult; Median age 55 (control) and 57 (intervention)	Breast cancer	Ambulatory	Multicenter 4 centers	RCT	Nurse-delivered intervention to address needs	Assessment and coaching on self-care, stress reduction, communication strategies, summary provided to physician; telephone follow-up at 1 week

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting(s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Aubin, 2006 ⁵	Adult, mean age 65	Mixed cancer population	Home care	Multi-center, four community based primary care centers providing home care services	Controlled trial, follow up collected at baseline, 2 weeks, and 4 weeks	One-time educational intervention	Included a pain diary, didactic material including a 15 minute video tape and a booklet, and pain monitoring recommendations
Badger, 2009 ⁶	Adults, no age reported	Mixed illnesses	Nursing home	Multicenter, 49 homes	Controlled trial, before-after	Gold Standards Framework in Care Homes	Includes identifying individuals' needs, assess and treat their needs and symptoms, Improve coordination within institution and outside, reducing avoidable hospital admissions.
Bailey, 2005 ⁷	Adult, 68	Mixed illnesses	Hospital	Single, 135 beds	Controlled trial, before-after	Inpatient Comfort Care Program	Intervention included staff education and support to identify patients who were actively dying and implement care plans guided by a comfort care order set template for the last days or hours of life
Bakitas, 2009 ⁸	Adult, 65	Cancer mixed	Ambulatory	Multicenter, 2 centers	RCT, 3 months or until patient die	Multi-component, psycho educational intervention	The intervention (telephone calls), based on the chronic care model, used a case management, educational approach to encourage patient activation, self-management, and empowerment
Blumenthal, 2006 ⁹	Adult	Lung disease	Home	Multicenter-2	RCT, 12 weeks	Telephone - based coping skills training	Lung transplant candidates - 12 weeks - supportive counseling and training in cognitive- behavioral coping skills, by social worker or psychologist; per protocol; education on stress and health

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Bookbinder, 2005 ¹⁰	Adult, >70	Mixed illnesses	Hospital,	Single, 5 units	Controlled trial(before-after), 4 months	Palliative Care for Advanced Disease pathway	Includes a care path, a daily flow sheet, and a physician order sheet with standard orders for symptom control
Borneman, 2008 ¹¹	Adult, mean age 64	Lung cancer	Ambulatory	Single	Controlled trial, follow up at 1 month and 3 months post intervention	4-part educational intervention delivered by a nurse to address pain and fatigue.	Information pertaining to pain assessment, pain management, fatigue assessment, and fatigue management was provided follow by bi-weekly phone contact
Borneman, 2010 ¹²	Adult; mean age 59.7 years	Mixed cancer population	Ambulatory	Single	Controlled trial, outcome measures for both control and intervention collected at baseline, 1 month, and 3 months post intervention	Intervention group received four educational sessions on painfatigue assessment and management. Written material on self-management of fatigue and pain also distributed.	NCCN Supportive Care Guidelines, "Passport to Comfort"
Brumley, 2003 ¹³	Adult, 74	COPD, CHF, cancer	Home care	Multicenter, 3 Kaiser Permanente	Controlled trial, 60 days	Home-Based Palliative Care	The care team (patient and family plus a physician, nurse, and social worker) is responsible for coordinating and managing care and providing assessment, evaluation, planning, care delivery, follow-up, monitoring and continuous reassessment of care

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Brumley, 2007 ¹⁴	Adult, 72	COPD, CHF, cancer	Home care	Multicenter, 2 HMO	RCT, 120 days	Home-Based Palliative Care	The care team (patient and family plus a physician, nurse, and social worker) is responsible for coordinating, managing care and providing assessment, evaluation, planning, care delivery, follow-up, monitoring and continuous reassessment of care
Burns, 2003 ¹⁵	Adult mean age 61years	Mixed illnesses	ICU	Multicenter (7 ICU)	Non-randomized controlled trial	Intervention to facilitate deliberative decision making.	Social workers interviewed families of patients at high risk for decisional conflict and provided feedback to clinicians to facilitate decision making
Campbell, 2003 ¹⁶	Adult	Mixed	ICU	Single center	Pre-post study	Proactive case-finding approach to palliative care consultation	Trigger criteria were used for medical ICU patients with global cerebral ischemia after CPR or with >3 system organ failure. Proactive palliative care was incorporated in the care of patients who met criteria.
Campion, 2011 ¹⁷	Adult	Mixed Cancer	Ambulatory	Multicenter	Controlled trial; not reported	Voluntary self-examination and process improvement system	Twice-yearly data reporting and analysis cycle and offers participating practices extensive, site-specific, and benchmarking reports that describe the continuum of care
Carlson, 2010 ¹⁸	Adult; 63.5 (control), 61.5 (Full) and 62.7 (triage)	Mixed cancer	Ambulatory	Single Center	RCT, 3 months	Distress screening with optional resource referral	Distress thermometer, problem checklist, psychological screen for anxiety and depression, personalized report and personalized phone triage with referral to resources

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Casarett, 2005 ¹⁹	Adult, 84	Mixed illnesses	Nursing home	Multiple. 3 sites	RCT, 6 months	Identify nursing home residents preference for hospice care	A structured interview identified residents whose goals for care, treatment preferences, and palliative care needs made them appropriate for hospice care. The residents' physicians were notified and asked to authorize a hospice informational visit
Clayton, 2007 ²⁰	Adult mean age: 65 (CONTROL 64.6, INTERVENTIO N 65.5)	Mixed cancer population	Other: Palliative care centers	9 centers	RCT	Question prompt list for patient consultation	Assists patients to ask questions about end-of-life issues and improve patient-physician communication
Cohen, 2010 ²¹	Adult, 70	Dialysis patients with poor prognosis	Ambulatory	Multicenter, 5 centers	Controlled trial, 17 months	Intervention to facilitate hospice referral	Organization of Renal supportive care teams who contacted subjects and/or family members to encourage advance care planning, discuss hospice resources, and offer general support
Dalton, 2004 ²²	Adult, mean age: 52	Mixed cancer population	Ambulatory	Multicenter - 3 cancer treatment centers and 1 hospital	RCT with three groups - follow up for 6 months	Profile-tailored CBT treatment program, matching individual responses to pain to specific CBT interventions	Five one-hour treatment sessions
Daly, 2010 ²³	Adult patients mean age 56years and family caregivers mean age 53years	Mixed illnesses	ICU	Multicenter (5 ICU)	Other (Pre-Post design)	An intensive communication system	The ICS included a family meeting within 5 days of adm to assist in goal setting, facilitate decision making, and reduce use of ineffective resources in the ICU; family meeting than weekly after.

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Detmar, 2002 ²⁴	Adult; 57	Mixed cancer	Ambulatory	Single center	RCT; timing of follow-up not reported	Pre-consultation HRQL questionnaire	HRQL questionnaire at 3 consecutive visits, with graphic summary given to patients and physicians before consultation
Du Pen, 2000 ²⁵	Adult, mean age 61 years	Mixed Cancers	Ambulatory	Multiple (9)	RCT by institution blocks, 4 months	Educational intervention to transfer knowledge on implementing a previously tested algorithm for cancer pain management - provider focused	Role model physiannurse teams were the core faculty for a day-long seminar. Written reference materials and documentation tools were provided to the trained physiannurse teams.
Dudgeon, 2008 ²⁶	Adult, 66	Mixed cancer	Ambulatory, hospital, home care	Multicenter, 5 sites?	Controlled trial, 12 months(for intervention)	PCIP=palliative care integration project.	Implementation of common assessment tools, collaborative care plans, and symptom management guidelines.
Engelhardt, 2006 ²⁷	Adult, 70	COPD chronic heart failure, mixed cancer	Hospital, home care	Multicenter, 4 sites	RCT, 3 and 6 months	AICCP= advanced illness coordinated care program.	6 sessions with care coordinator helps with provider communication, care coordination, and support
Fuchs-Lacelle, 2008 ²⁸	Adult, mean age ~85 years	Dementia	Nursing Homes	12 (average number of beds was 56)	RCT (at the nursing unit level), comparative longitudinal design, 3 months	Nurse -led systematic pain assessment	Nursing staff regularly assessed dementia patients' pain through the use of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Gade, 2008 ²⁹	Adult mean age: 73.6	Mixed illnesses	Hospital	3 hospitals	RCT	Interdisciplinary palliative care service for patients.	The IPCS teams included a palliative care physician and nurse, hospital social worker and chaplain. The team met prior to each consultation to share what was known about the patient from the medical record, baseline questionnaire, and hospital providers. The entire team then met with the patient/family to address symptoms, diagnosis, prognosis, and goals of care.
Given, 2002 ³⁰	Adult, intervention: 59 years, control: 57 years	Mixed cancer population	Ambulatory	Multicenter - 2 comprehensive cancer centers, 2 community oncology clinics	RCT, 20 weeks	Nurse implemented pain and fatigue management through patient education and support	Consisted of 10 contacts, 6 in person and 4 via telephone, occurring at two-week intervals over a 20-week period using evidence-based computer guidance for problem solving with patients
Hanks, 2002 ³¹	Adult mean age 68.4	Mixed illnesses	Hospital	Multicenter	RCT	Full palliative care team advice and support	The effectiveness of a hospital Palliative Care Team on physical symptoms and health-related quality of life of patients and family caregiver.
Hudson, 2005 ³²	Adult	Caregivers of patients dying of cancer at home	Home	Two community (home based)	RCT	Evaluation of psycho-educational	
Hughes, 2000 ³³	Adult, mean age 70 for study overall	Mixed illnesses	Home care	Multi, 16 sites	RCT, 1 year or until death	Team-Managed Home-Based Primary Care	Home-based primary care including a primary care manager, 24-hour contact for patients, prior approval of hospital readmissions, and HBPC team participation in discharge planning

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Jacobsen, 2011 ³⁴	Adult mean age 62.9 (control), 63.5 (intervention)	Mixed illnesses	Hospital	Single center	Controlled trial	Cognitive model for advance care planning (ACP) discussion	Nursing and physician education about how to approach ACP, focused ACP discussions (information-sharing meetings and/or decision making meetings) with patients and families
Jordhoy, 2000 ³⁵ Jordoy, 2001 ³⁶ , Ringdal 2002 ³⁷ , Ringdal, 2001 ³⁸	Adult, 68	Mixed cancer	Home, ambulatory, and palliative medicine unit	Single center - 12 bed unit palliative medicine unit	Cluster RCT,	Comprehensive palliative care	Multidisciplinary approach to care, outpatient and inpatient managed by PMU , PMU staff served as link to community, community education, predefined guidelines for interaction between palliative care and community
Kaufer, 2008 ³⁹	Adult patients mean age unclear (Just stated above 50 years and below 50 years)	Mixed illnesses	ICU	Single center	Other (Pre-Post design)	An intervention consisting of early communication, family meetings, and psychosocial support with support by the hospital palliative care team and family support team.	To improve the quality of end-of-life care, particularly by increasing family members' satisfaction with decisionmaking, communication with physicians and nurses, and the death and dying process.
Keefe, 2005 ⁴⁰	Adult, mean age 60.5 years	Mixed cancer population	Home care	Multi-center - recruited from an unspecific number of hospices as well as two major cancer centers	RCT, approximately 20 days	Nurse-led partner-guided pain management intervention -three sessions	Nurse-led intervention to educate patient and partner about pain and pain management and to train the partner to support the patient in pain management

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Kovach, 2006 ⁴¹	Adult, mean age 86.5	Dementia	Nursing Homes	Multisite: 14 Nursing Homes, average of 114 beds	RCT	Serial trial intervention, a protocol of assessing needs of people with dementia	Intervention to identify behavioral symptoms of discomfort by using an explicit schedule and procedures for nurses and ancillary staff
Lautrette et al, 2007 ⁴²	Adult, median age 68 in control, 74 in intervention	Mixed - ICU population	Hospital - ICU	Multi-center, all in France, 22 icus, median of 16 bedsICU	RCT	Proactive EOL conference & brochure	Family conference used detailed guidelines with five objectives of VALUE pneumonic and families given bereavement brochure.
Lilly, 2000 ⁴³	Control - mean age 60, intervention - mean age 58	Mixed illnesses	ICU	Single center	Prospective; before and after study	Intensive communication and use of critical care	Multidisciplinary family meetings at 72 hrs after admission to ICU. Process that was designed to encourage the use of advanced supportive technology when it is of benefit, but to limit its burdens when it is ineffective.
Lilly, 2003 ⁴⁴	Adult mean age: 59	Mixed illnesses	ICU, Hospital	Single center	Other prospective: 4-year follow-up	Intensive communication for patients or family by providers	A defined, coordinated, proactive process of communication in which an initial formal family meeting was preceded by communication among providers with regard to the plan of care and the outcome goals.

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Lovell, 2010 ⁴⁵	Adult; 62	Mixed cancer	Hospital	Multicenter: 21	RCT, four weeks	Pain management educational intervention, four treatment arms - 1) standard care, 2) standard care plus a booklet, 3) standard care plus a video, 4) standard care plus a booklet and a video	Educational intervention consisting of a booklet for adults with cancer pain designed to improve knowledge and attitudes about cancer pain management, pain levels, pain interference, anxiety, QOL, and analgesic use - single contact
Luhrs, 2005 ⁴⁶	Adult, 72	Mixed illnesses	Hospital,	Single, 3 units	Controlled trial(before-after), follow up unclear	Palliative Care for Advanced Disease (PCAD) pathway	Includes a care path, a daily flow sheet, and a physician order sheet with standard orders for symptom control
Marinangeli, 2004 ⁴⁷	Adult; control: 61.3, intervention: 63.9	Mixed cancer population	Ambulatory	Single	RCT, follow up to patient death	Use of strong opioids as the 1st step in pain management versus the WHO analgesic ladder	Comparison group- WHO guidelines where strong opioid is first line, all other pain treatments were the same; palliative care pts
Mcmillan, 2011 ⁴⁸	Adult, 73	Mixed cancer	Hospice	Multicenter, 2 sites	RCT, 2 weeks	Systematic feedback of standardized assessment to IDTS	Standardized assessment followed by two interdisciplinary team discussions
Miaskowski, 2004 ⁴⁹ Miaskowski, 2007 ⁵⁰	Adult, mean age intervention: 60.0, control: 58.8	Mixed cancer population	Ambulatory	Multi-center, 7 centers	RCT, six weeks	Nurse-led psycho-educational intervention - in person contacts at weeks 1, 3, and 6, phone contact at 2,4, and 5	PRO-SELF group patients were seen by specially trained nurses; psycho-educational intervention - given written instructions on how to communicate with their physician about unrelieved pain
Mills, 2009 ⁵¹	Adult, 64	Lung cancer	Hospital	3 center	RCT, 16 weeks	Weekly QOL questionnaire	QOL questionnaire, patients are encourage to share it with health care provider

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Mitchell, 2008 ⁵²	Adult, median age between 65-72	Mixed illnesses	Ambulatory, hospital	Multicenter, 2 centers	RCT, 3 weeks(for primary outcome)	Specialist- GP case conferences	GP phoning in to a routine specialist team meeting
Molloy, 2000 ⁵³	Adult mean age 83.14 (calc from Table 1)	Mixed illnesses	Nursing homes	Multicenter	RCT	The let me decide advance directive program included educating providers, patients and families about advance directives	Educating staff in local hospitals and nursing homes, residents, and families about advance directives and offering competent residents or next-of-kin of mentally incompetent residents an advance directive that provided a range of health care choices for life-threatening illness, cardiac arrest, and nutrition.
Moore, 2002 ⁵⁴	Adult, 67	Lung cancer	Ambulatory	Multicenter4 centers	RCT, 3 months	Nurse led follow up	Nurse specialists assessed patients monthly or as needed by phone or in clinic to identify disease progression, symptoms warranting intervention, or serious complications
Mosenthal, 2008 ⁵⁵	Adult mean age 40 years	Trauma	ICU	Single center 14bed ICU in an academic tertiary care center	Prospective	Structured communication between physician and families of dying trauma patients.	Bereavementpsychosocial support for patients and families, Interdisciplinary family meeting with physician and nurse
Meyers, 2011 ⁵⁶	Adult	Mixed Cancer	Not Specified Cancer Centers	Multicenter	Randomized Controlled Trial	Education sessions to learn COPE problem solving model	Dyads participating in three conjoint educational sessions during the first month, learning the COPE problem solving model.

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Norton, 2007 ⁵⁷	Adult, 76	CHF, COPD, mixed cancer, Cirrhosis	Hospital	Single, 560 bed	RCT, 2 weeks after discharge	Hospital-Based Palliative Medicine Consultation	5week during hospitalization the PMC physician assessed symptoms, psychosocial and spiritual needs, discussed treatment preferences, consulted pharmacist and chaplain as needed, communicated findings and recommendations to the patient's team via a medical chart note and by phone.
Penticuff, 2005 ⁶²	Pediatrics (Very low birth weight infants immediately after birth)	Other	NICU (neonatal ICU)	2 centers	Controlled trial	Infant Progress Chart and Care Planning Meetings	An intervention to improve parents' comprehension of infant medical condition and satisfaction with collaboration in treatment decisions - care planning, 3 meetings, including goal-setting with complications and development of poor prognosis
Porter, 2011 ⁶³	Adult	Lung Cancer Stage I,II or III	Ambulatory	Multicenter	RCT	Care giver-assisted coping skills training	
Rabow, 2004 ⁶⁴	Adult, 68 years	COPD, CHF, cancer	Ambulatory	Single	12 months, controlled trial	Comprehensive Care Team	Primary care physicians received multiple palliative care team consultations, and patients received advance care planning, psychosocial support, and family caregiver training.
Reymond, 2011 ⁶⁵	Adult	Mixed Illnesses, mean age not reported	Nursing home	Multicenter, 7 sites	non-RCT	Residential aged end-of-life care pathway	Identifying and training nurse champions, networking facilities with specialty palliative care, educating physicians, development and implementation of end-of-life clinical management care pathway

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Rosenbloom, 2007 ⁶⁶	Adult	Breast, lung, colorectal	Ambulatory	Single center	RCT, 6 months	Health related quality of life (HRQL) assessment of patients	HRQL assessments given to treating nurse in 1 group; in another group, HRQL assessment followed by structured interview and discussion
Sampson, 2011 ⁶⁷	Adult mean age: 87	Advanced dementia	Hospital: acute medical wards	single	RCT	Palliative care consultation and advanced care plan discussion with carer.	The clinical team had structured discussions with carers to understand cultural, spiritual, health, social and financial needs experienced by the carer and the psychological support available to them. They inquired whether the person with dementia had made any previous advance directives or statements or had expressed any preferences for care. They provided basic education on dementia as a neuro-degenerative disease, the prognosis of advanced dementia, the role of palliative care (focusing on palliative care as appropriate active care, NOT withdrawal of treatment) and advance care planning.
Schneiderman, 2000 ⁶⁸	Control - mean age 45.9, intervention - mean age 52.4	Mixed illnesses	ICU	Single center	RCT	Impact of ethics consultations on patients, families and providers	

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Schneiderman, 2003 ⁶⁹	Adult mean age 67.5 - both groups	Mixed illnesses	ICU	Multicenter	RCT	Ethics consultations to resolve conflicts about life-sustaining interventions.	
Steel, 2007 ⁷⁰	Adult	Hepa-tobiliary	Ambulatory	Single center	RCT	Individually tailored psychosocial intervention	Patients chose from list of concerns which were most distressing (symptoms, psychological, and end of life issues) and strategies offered to treat each problem
Syrjala, 2008 ⁷¹	Adult, 57.77 for intervention, 53.37 for control	Mixed cancer population	Ambulatory	Multicenter: 6 centers	RCT, six months	Patient training in cancer pain management using integrated print and video materials	Study RN reviewed materials with the patient; patient filled out checklist with RN on barriers to pain relief, and reviewed with RN; patient encouraged to take checklist to next doctor's appt; 1 10-minute follow-up
Taenzer, 2000 ⁷²	Adult	Lung cancer	Ambulatory	Single center	Controlled trial, duration not specified	Provide patient-specific QOL info to staff before appointments	Staff instructed in how to use the QOL report to identify specific domains to guide their discussion
Temel, 2010 ⁷³	Adult (65years)	Metastatic lung cancer	Ambulatory	Single center (Hospital: oncology clinic)	RCT, 12 weeks	Early palliative care integrated with standard oncologic care	Palliative care physician advance practice RN outpatient consultation within 3 months of diagnosis and at least monthly thereafter; based on palliative care guidelines, including physical and psychosocial symptoms, goals of care, decision making regarding treatment, and coordinating care; concurrent with usual oncology care

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Tulsky, 2011 ⁷⁴	Intervention 62.2, Control 59.9	mixed cancer population	Oncology outpatient clinic	multicenter	RCT	Computer based training to improve communication between oncologists and patients	Oncologists in the intervention group received an interactive CD-ROM training program on communication skills that was tailored with exemplars from their own audio-recorded clinic visits. This intervention was designed to enhance oncologists' ability to respond effectively to patients' emotional concerns.
Van der Peet, 2004 ⁷⁵	Adult, intervention: 62, control: 60.5 years	Mixed cancer population	Home care	Multicenter - outpatient clinics and one radiotherapy department	RCT, 8 weeks	Nursing-based pain education program - three home visits	The PEP consists of the following three components: (1) enhancement of patients' pain knowledge and pain management by means of a brochure, (2) instruction of patients as to how they should record their pain intensity in a pain diary, and (3) stimulation of patients' help-seeking behavior.
Vd heide, 2010 ⁷⁶	ADULT, 64-75	Mixed cancer	Hospital, nursing home, home care	Multicenter. 6 centers or organizations	Controlled trial (before-after),	Liverpool Care Pathway for the Dying Patient	Structuring care in the last days of life and at facilitating audit by standardizing the monitoring of care
Velikova, 2004 ⁷⁷ ; Velikova, 2010 ⁷⁸	Adult; 54.9 (12.3)	Mixed cancer	Ambulatory	Single center	RCT; unclear (3 visits)	Health-related quality of life survey with feedback to physicians	Patients were (1) asked to complete a touch-screen HRQOL survey that provided feedback to physicians or (2) asked to complete the HRQOL survey that did not provide feedback or (3) were not asked to complete a survey - 3 visits; providers were provided detailed training & asked to review & use the HRQOL information during encounters

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Walsh, 2007 ⁷⁹	Adult; 56.3	Mixed cancer	Home, ambulatory	3 cancer networks	RCT	Career-focused intervention added to palliative care	Six visits to careers by advisors with background in nursing and social work: needs assessment, advice and support focusing on 7 domains of care
Ward, 2000 ⁸⁰	Adult, 58 years	Gynecologic Cancers	Ambulatory	Single	RCT, two months	Nurse led individually tailored information	Concerns (barriers) and side effect management, used a booklet developed through comprehensive process, tailored based on patient's barriers and side effects questionnaire; with booster follow-up call
Ward, 2008 ⁸¹	Adult, 55.11 years	Mixed cancer population	Ambulatory	Multicenter - 2 clinics	RCT, two months	Educational intervention based on the representational approach to patient education	Single 1:1 face-to-face psycho educational session that lasts from 20 minutes to an hour.
Wells, 2003 ⁸²	Adult, 53 years	Mixed cancer population	Ambulatory	Single	RCT, six months	Two interventions 1) Pain education with a hot line 2) Pain education with provider-initiated follow-up telephone calls, compared to usual care control	All treatment arms were shown a videotape and received individual counseling - both intervention arms had access to a hotline, the telephone follow up intervention arm received four follow up calls
Wilkie, 2010 ⁸³	Adult; mean age intervention: 63.4, mean age controls: 60.1	Lung cancer	Ambulatory	Multicenter - 11 sites	RCT, 4 weeks	Individualized pain coaching on self monitoring and reporting	12-minute videotape of trained actress - pain perception and monitoring, instruction in using a Coaching tool at home and giving information to their provider; also several reinforcement coachings

Evidence Table 1. Population and study characteristics of all included studies (continued)

Author, year	Population	Disease	Setting (s)	Single vs. Multicenter	Study Design	Description of intervention	Description of intervention
Woo, 2011 ⁸⁴	Adults,84	Mixed illnesses (majority dementia)	Rehabilitation and convalescent unit	Single, 227 beds	Controlled trial, before-after, 3 months	Continuous initiative (Plan-do-study-act)	Service reengineering, provision of guidelines and educational material, and interactive sessions to achieve culture change among staff.

Abbreviations: ACP=American College of Physicians; AICCP=Palliative Care Integration Project; CHF=Cardiac Heart Failure; COPD=Chronic Obstructive Pulmonary Disease; EOL=End of Life; HMO=Health Maintenance Organization; HRQL=Health Related Quality of Life; ICS=An intensive communication system; ICU=Intensive Care Unit; Medicine Consultation; NCCN=National Comprehensive Cancer Network; NICU=Neonatal Intensive Care Unit; PACSLAC=Pain Assessment Checklist for Seniors with Limited Ability to Communicate; PCIP=Palliative Care Integration project; PCS=Palliative Care Service; PMC=Palliative Management Care; PMU=Pain Management Unit; QPL=Question Prompts Lists; RCT=Randomized Control Trial

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Evidence Table 2. Description of interventions for studies addressing continuity, coordination of care, and transitions

Author, year	Integrative vs. consultative	Target of intervention
Aiken, 2006, ¹	Consultative: interacts with both	Case management, interdisciplinary assessment, symptom management, advanced care planning, overutilization
Badger, 2009 ²	Integrative	Communication, coordination, advanced care planning, over-utilization, symptom management
Bailey, 2005 ³	Integrative	Symptom management, coordination, interdisciplinary assessment, comfort care, over-utilization
Bakitas, 2009 ⁴	Consultative: interacts with patient/family	Case management, interdisciplinary assessment, transition, communication
Bookbinder, 2005 ⁵	Integrative	Interdisciplinary teams, communication, symptom management, support for families, case management
Brumley, 2003 ⁶	Consultative: interacts with both	Case management, interdisciplinary assessments, family support, communication, coordination
Brumley, 2007 ⁷	Consultative: interacts with both	Case management, interdisciplinary assessments, family support, communication, coordination, spiritual
Casarett, 2005 ⁸	Integrative	Transition, communication
Cohen, 2010 ⁹	Consultative: interacts with patient/family	Transition
Dudgeon, 2008 ¹⁰	Integrative	Pain, care giving, interdisciplinary assessment, coordination, documentation
Engelhardt, 2006 ¹¹	Combined: interacts with patient/family	Psychosocial support, communication, coordination, family support and care giving, advanced care planning, case management
Hughes, 2000 ¹²	Combined: Interacts with both	Transition, case management, interdisciplinary assessment
Jordhoy, 2000 ¹³ , Jordhoy, 2001 ¹⁴ , Ringdal, 2001 ¹⁵ , Ringdal, 2002 ¹⁶	Combined: interacts with both	Interdisciplinary team, symptom management, support for caregivers who had died from advanced cancer
Luhrs, 2005 ¹⁷	Integrative	Transition, case management, interdisciplinary assessment
McMillan, 2011 ¹⁸	Integrative	Interdisciplinary assessment
Mitchell, 2008 ¹⁹	Integrative	Interdisciplinary teams
Moore, 2002 ²⁰	Consultative: interacts with both	Case management, coordination, documentation
Pantilat, 2010 ²¹	Consultative: interacts with both	Interdisciplinary assessments, communication, documentation
Rabow, 2004 ²²	Consultative: interacts with both	Case management, communication, interdisciplinary teams, interdisciplinary assessments, psychosocial/spiritual support, physical symptoms
Reymond, 2011 ²³	Integrative	Coordination, care planning, symptom management
Temel, 2010 ²⁴	Consultative: interacts with both	Physical and psychosocial symptoms, goals of care, treatment decision making and coordinating care

Evidence Table 2. Description of interventions for studies addressing continuity, coordination of care, and transitions

Author, year	Integrative vs. consultative	Target of intervention
Van der Heide, 2010 ²⁵	Integrative	Interdisciplinary assessment, communication, symptom management, transition
Woo, 2011 ²⁶	Integrative	Communication, coordination, documentation

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Evidence Table 3. Description of quality improvement elements in studies addressing continuity, coordination of care, and transitions

Author, year	Provider reminder system?	Facilitated relay of clinical data to providers?	Audit and feedback?	Provider education?	Coaching collaborative skills training?	Patient family caregiver education?	Promotion of self-Management?	Organizational change?	Other?
Aiken, 2006 ¹	No	Yes	No	No	No	Yes	Yes	Yes	No
Badger, 2009 ²	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No
Bailey, 2005 ³	Yes	Yes	No	Yes	Yes	No	No	No	No
Bakitas, 2009 ⁴	No	No	No	No	No	Yes	Yes	Yes	No
Bookbinder, 2005 ⁵	Yes	Yes	No	Yes	Yes	No	No	No	No
Brumley, 2003 ⁶	No	No	No	Yes	No	Yes	Yes	Yes	No
Brumley, 2007 ⁷	No	No	No	Yes	No	Yes	Yes	Yes	No
Casarett, 2005 ⁸	No	Yes	No	No	No	No	No	No	No
Cohen, 2010 ⁹	No	No	No	No	No	No	No	Yes	No
Dudgeon, 2008 ¹⁰	Yes	Yes	No	Yes	No	No	No	No	No
Engelhardt, 2006 ¹¹	No	Yes	No	No	No	Yes	Yes	Yes	No
Hughes, 2000 ¹²	No	No	No	No	No	No	Yes	Yes	No

Evidence Table 3. Description of quality improvement elements in studies addressing continuity, coordination of care, and transitions (continued)

Author, year	Provider reminder system?	Facilitated relay of clinical data to providers?	Audit and feedback?	Provider education?	Coaching collaborative skills training?	Patient family caregiver education?	Promotion of self-Management?	Organizational change?	Other?
Jordhoy, 2000 ¹³ , Jordhoy, 2001 ¹⁴ , Ringdal, 2001 ¹⁵ , Ringdal, 2002 ¹⁶	No	No	No	Yes	No	Yes	Yes	Yes	No
Luhrs, 2005 ¹⁷	No	No	No	No	No	No	Yes	Yes	No
McMillan, 2011 ¹⁸	Yes	Yes	No	No	No	No	No	Yes	No
Mitchell, 2008 ¹⁹	No	Yes	No	No	No	No	No	Yes	No
Moore, 2002 ²⁰	No	Yes	No	No	No	No	No	Yes	No
Pantilat, 2010 ²¹	Yes	Yes	No	No	No	No	No	Yes	No
Rabow, 2004 ²²	No	Yes	No	No	No	Yes	No	Yes	No
Reymond, 2011 ²³	Yes	No	N	Yes	N	No	No	No	No
Temel, 2010 ²⁴	No	No	No	No	No	Yes	Yes	No	Yes

Evidence Table 3. Description of quality improvement elements in studies addressing continuity, coordination of care, and transitions (continued)

Author, year	Provider reminder system?	Facilitated relay of clinical data to providers?	Audit and feedback?	Provider education?	Coaching collaborative skills training?	Patient family caregiver education?	Promotion of self-Management?	Organizational change?	Other?
Van der Heide, 2010 ²⁵	Yes	No	No	No	No	No	No	No	No
Woo, 2011 ²⁶	Yes	Yes	No	Yes	Yes	Yes	No	No	No

Evidence Table 3 Reference List

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Evidence Table 4. Risk of bias assessment of studies addressing continuity, coordination of care, and transitions

Author, year	Sequence generation	Allocation concealment	Binding of personnel (short-term outcomes)	Blinding of outcome assessors (short-term outcomes)	Binding of personnel (long-term outcomes)	Blinding of outcome assessors (long-term outcomes)	Incomplete outcome data (short-term outcomes)	Incomplete outcome data (long-term outcomes)	Selective outcome reporting	Other sources of bias
Aiken, 2006 ¹	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Unclear	Yes
Badger, 2009 ²	No	No	No	No	No	No	No	No	Unclear	Yes
Bailey, 2005 ³	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Bakitas, 2009 ⁴	Yes	Unclear	No	Unclear	No	Unclear	Yes	Yes	Yes	Yes
Bookbinder, 2005 ⁵	No	No	No	No	No	No	Yes	Yes	No	No
Brumley, 2003 ⁶	No	No	No	Yes	No	Yes	Unclear	Unclear	Yes	Yes
Brumley, 2007 ⁷	Yes	Yes	No	Yes	No	Yes	Yes	Yes	No	No
Casarett, 2005 ⁸	Yes	Yes	No	No	No	No	Yes	Yes	Yes	Yes
Cohen, 2010 ⁹	No	No	No	No	No	No	Unclear	Unclear	Yes	Yes
Dudgeon, 2008 ¹⁰	No	No	No	No	No	No	Unclear	Unclear	Yes	Yes
Engelhardt, 2006 ¹¹	Yes	Unclear	No		No	No	No	No	No	Yes
Hughes, 2000 ¹²	Yes	Unclear	No	No	No	No	Yes	Yes	Yes	Yes
Jordhoy, 2000 ¹³ , 2001 ¹⁴ , Ringdal, 2001 ¹⁵ , 2002 ¹⁶	Unclear	Unclear	No	No	No	No	Yes	No	Yes	Yes
Luhrs, 2005 ¹⁷	No	No	No	No	No		Yes	Yes	Yes	Yes
McMillan, 2011 ¹⁸	Unclear	No	No	No	No	No	Unclear	Unclear	Yes	Yes
Mitchell, 2008 ¹⁹	Yes	Yes	No	No	No	No	Yes	Yes	No	No
Moore, 2002 ²⁰	Yes	Yes	No	No	No	No	Unclear	Unclear	Yes	Yes
Pantilat, 2010 ²¹	Unclear	No	No	Yes	No	Yes	Unclear	Unclear	Yes	No
Rabow, 2004 ²²	No	No	No	No	No	Yes	Yes	Yes	Yes	Yes

Evidence Table 4. Risk of bias assessment of studies addressing continuity, coordination of care, and transitions

Author, year	Sequence generation	Allocation concealment	Binding of personnel (short-term outcomes)	Blinding of outcome assessors (short-term outcomes)	Binding of personnel (long-term outcomes)	Blinding of outcome assessors (long-term outcomes)	Incomplete outcome data (short-term outcomes)	Incomplete outcome data (long-term outcomes)	Selective outcome reporting	Other sources of bias
Reymond, 2011 ²³	No	No	No	No	No	No	Y	Yes	No	No
Temel, 2010 ²⁴	Unclear	Unclear	No	No	No	No	Yes	Yes	No	Yes
Van der Heide, 2010 ²⁵	No	No	No	No	No	No	Unclear	Unclear	Yes	Yes
Woo, 2011 ²⁶	No	No	No	No	No	No	Unclear	Unclear	No	Yes

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24. Temel JS, Greer JA, Muzikansky A *et al*. Early palliative care for patients with metastatic non-small-cell lung cancer. *The New England Journal of Medicine* 2010; 363(8):733-42.
25. van der Heide A, Veerbeek L, Swart S, van der Rijt C, van der Maas PJ, van Zuylen L. End-of-life decision making for cancer patients in different clinical settings and the impact of the LCP. *J Pain Symptom Manage* 2010; 39(1):33-43.
26. Woo J, Cheng JO, Lee J *et al*. Evaluation of a continuous quality improvement initiative for end-of-life care for older noncancer patients. *J Am Med Dir Assoc* 2011; 12(2):105-13.

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Aiken, 2006 ¹	QOL	SF 36	192	None		68 measurements=NS		Difficulties with recruitment led to smaller enrollment than planned; Significant attrition (13 died or went to hospice in 1st 3 months) (only 25% of control group still participating at end of data collection); reported that COPD showed stronger response
	Patient symptoms	Memorial Symptom Assessment Scale				Frequency and severity=NS		
	LOS					LOS=NS		
	Other	AD			71% vs. 65% p =0.05, OR 4.47, [CI: 1.10, 18.18]			Statistics not reported at time 6 where it would be NS
	Quality of care measures	Self management and knowledge				46 and 36 measurements at all time point=NS		
Badger, 2009 ²	Other	Death in the care home	437	None	81% before vs. 88.5% after, p<0.001			Evidence that the GSF was implemented in the care homes; Crisis events, advanced care plan in place, access to as required medications, last days of life care pathway, written information to family all significantly Improved
	Other	Crisis hospitalization			38% vs. 26% after, p=0.001			

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Bailey, 2005 ³	Other	DNR orders	203	None	61.9% vs. 85.1% (P=□.001)		Significant increase in documented use of restraints	This intervention went beyond ordinary education to facilitate change in staff practice patterns by providing tools (pocket card reminders, supportive policy changes, and a structured order set) to reinforce and guide care plans; concurrent implementation of other restraint policies may have caused restraint finding; also significant increase in documentation of care plans
	Other	Location of death				Patients dying in ICU		
	Other	Opioid orders at death			57.1% vs. 83.2% (P=□.001).			
	Other	Nasogastric tube at death				NS		
	Quality of care measures	Symptom documentation			1.7 (SD 2.1) vs. 4.4 (SD 2.7) (P=□.001)			
Bakitas, 1077 ⁴	QOL	Functional Assessment of Chronic Illness Therapy for Palliative Care	322	None	Intervention: higher QOL (mean [SE], 4.6 [2]; P=.02);		None	
	Patient symptoms	ESAS				Symptom intensity		
	Resource use					Hospital LOS, ICU LOS, # ER visits; survival		
	Psycho-social symptoms and support	CES-D			Mood: CES-D score, (mean[SE], -1.8 [0.81]; p=0.02)			

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Bookbinder, 2005 ⁵	Symptoms assessed, problematic symptoms identified, # interventions, # inpatient consultations	Chart Abstraction Tool (CAT) - indices on admission Referral data, end-of-life decision making, symptom assessment management, death, and resource utilization data	257	None		Number of symptoms assessed increased significantly in both comparison and study units.(Only within group comparisons)		Pilot testing. Some CAT indices increased significantly on all units - possible indication of diffusion of educationcultural change despite not implementing the pathway; other changes were significant in the inpatient palliative care unit but not in the geriatrics or oncology units - 100% of patients in the inpatient palliative care unit but only 33% of patients in the latter 2 units were placed on the pathway; non-VA setting
Brumley, 2003 ⁶	Satisfaction	Reid-Gundlach satisfaction of service	300	None		Within-group comparison= useless		Lowered service use and costs while maintaining satisfaction.
	Service use				F=13.953; p = 0.001			
	Cost				\$7,990 vs.\$14,570 p<.001			
	Satisfaction	Reid-Gundlach satisfaction of service	297	None	At 30 days OR=3.37, 95% CI=1.42–8.10; P=.006 and 90 days,(OR=3.37, 95% CI=0.65–4.96; P=.03)	At 60 days		

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Brumley, 2003 ⁶ (continued)	Service use				ED visits: 20% vs. 33% p=0.01, hospitalizations : 36% vs. 59% p<.001. LOS p<.001			
	Cost	Overall costs			P=.03; 95% CI= \$12,411 to \$780			
Casarett, 2005 ⁷	Hospice enrollment	Enrollment within 30 days	205	None reported in results	21107 [20%] vs. 198 [1%]; P= .001; 95% confidence interval [CI], 1.34-5.19(number needed to treat [NNT]=5).			Also significantly different - hospice enrollment within 6 months, # of acute care admissions, and days spent in an acute care setting
	Quality of care measures	Toolkit After death Survey			4.3(SD 1.01) vs. 2.2 (1.47), p=0.01			
	Hospice enrollment	At time of death				Enrolled in hospice at time of death		
	LOS				LOS			
	Location of death					The resident died where heshe would have wanted		
Cohen, 2010 ⁸	Use of hospice services		133	None		Use of hospice services	None	In a subgroup of patients >65 the primary outcome of utilization of hospice services improved significantly (p<0.05)
	Discontinuation of dialysis					Discontinuation of dialysis		

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Dudgeon, 2008 ⁹	Patient symptoms	Edmonton Symptom assessment scale ,	200	None		ESAS(NS),Symptom score(NS)	None	The study showed minimal improvements. Challenge: conducted during SARS. Lessons: takes longer to implement projects than anticipated, standardized documentation should be in place prior to initiating such a project
	Satisfaction	FAMCARE Scale,				FAMCARE(NS),		
	Frequency and duration of hospital stay	Chart Audits,			AC admission (p<0.001) 476513 patients (92.8%) in 2001 vs 497570 (87.2%) in 2002, 498579 in 2003 (86.0%)	Death(NS), Chart Audits (35=NS),		
	Psycho-social symptoms and support; Caregiver burden	Care-giver assessment				CRA(NS)		
	Quality of care measures; Location of death,					Location of death (NS),		

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Engelhardt, 2006 ¹⁰	Satisfaction	EOL Family interview, Likert scale,	275	None	Patient satisfaction (p=0.03, effect size=0.18),	Attitudes about participation in treatment decisions (NS),	None	Don't report all caregiver outcomes
	Quality of care measures; Documentation,				Problems reported by surrogates (p=0.03, effect size=0.39),			
	AD and DNR, cost				AD (p=0.01)	Cost, DNR		
Hughes, 2000 ¹¹	QOL	MOS SF-36	188 patients, 289 caregivers	None	68 scales improved for both patients and caregivers			Abstracted the results for the terminally ill group only; utilization not reported separately for this group; Intervention is not described in detail
	Satisfaction; patient	Ware Satisfaction with Care scales				66 outcomes=NS		
	Functional status	Barthel score				NS		
	Psychosocial symptoms and support; Caregiver burden	Montgomery scale,				NS		
	Readmission					NS		
	Satisfaction; Caregiver				56 scales improved			

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Luhrs, 2005 ¹²	Quality of care measures	EOL-CAT	39	None	35 Interventions on last day decreased significantly, more patients were identified as dying and comfort care plan increased significantly, significantly more symptoms assessed and managed (0.5 comparison vs. 1.0 intervention, p=.02)		Increased LOS in PCAD group	Same intervention in a VA setting acute care oncology unit. QI interdisciplinary team and education of staff assisted in implementation; commitment of leadership and involvement of attending physicians, as well as discussion at monthly staff meetings; 64.7% of patients in the intervention period who died were placed on PCAD. No change in practice in a concurrently measured group on another unit. Family satisfaction was collected but response rate too low for analysis
Jordhoy, 2000 ¹³ , 2000 ¹⁴ , Ringdal 2002 ¹⁵ , 2001 ¹⁶	Quality of care measures; Place of death	Home or institution	434	Not addressed	More frequently home for intervention group (25%) than control group (15%), p=0.02 adjusted	No difference in survival		PC intervention allowed more pts to die at home, however no increase in overall proportion of time spent at home.
	Quality of care measures; % of nursing home deaths				Less frequent in intervention group (9%) than control group (21) p=0.01			PC led to less use of nursing homes, but in Norway nursing home beds are sometimes used as substitutes for inpatient hospital beds

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Jordhoy, 2000 ¹³ , 2000 ¹⁴ , Ringdal 2002 ¹⁵ , 2001 ¹⁶ (continued)	Days spent in hospital in the last month of life	Days in hospital				NS		
	% of hospital deaths					NS		Significantly less time spent in NH but % of admissions not different
	QOL	European Organization for Research and Treatment of Cancer Quality of Life-C30 EORTC QLQ-C30				NS		Possible reasons - conventional care is generally good for only marginal improvements (some control groups also focused on palliative care); also trial started just after the PMU was opened so may not have been optimally skilled; strongly based on community service with limited palliative care competence; study in Norway
	Other	Impact of Event Scales IES-measures how pts react to stressful events like having cancer				NS for psychological distress, pain, physical and emotional functioning p>.1		

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Ringdal, 2002 ¹⁵	Family members satisfaction with care	FAMCARE scale-looks at close family members satisfaction with care	182	Not addressed	Intervention group "reported lowest scores, that is highest satisfaction with care on all items except item 6 "availability of hospital bed, and item 14 times required to make diagnosis. In total 11 of 18 items were significant			Children of the deceased were least satisfied with care $p < .001$, males were more satisfied with care than females $p < .015$, "results should be interpreted with caution. Most close family members were aware that the trial was connected to the PMU and may have been reluctant to give criticism." More pts in the intervention group died at home than in the control group.
Ringdal, 2001 ¹⁶	Grief	Texas Revised Inventory of F=Grief-TRIG	183	Not addressed		NS differences in grief reactions between the family members of the two groups at any point in time.		"Attrition caused by refusal and withdrawal findings may not be representative for the two groups (intervention and control) and should be interpreted with caution" Attrition rate was higher in the control group
Mcmillan, 2011 ¹⁷	QOL	HQLI 14		None		NS		
	Patient symptoms	MSAS				NS		
		CES-D			Estimate -0.03, SE 0.01, $p = 0.02$			
		CES-D				NS		

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Mitchell, 2008 ¹⁸		Assessment of Quality of life at the End of Life	159	None		NS		
		Mcgill Quality of Life Questionnaire				NS		
	QOL; At 3 weeks	Subjective Wellbeing Scale				NS		
	Caregiver burden	Caregiver Reaction Assessment				Most time points =NS		
Moore, 2002 ¹⁹	QOL	European Organization for Research and Treatment of Cancer's core questionnaire	202	None		1314 items are NS		
	Satisfaction; Patient				55 items p>0.05			
	Survival					NS		
	Cost					NS		
	Use of service				Fewer admission to hospitals, more died at home	1116 items are NS		

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Pantilat, 2010 ²⁰	Pain scores	Scoring from 1-10	107	None		NS		Reasons for ineffectiveness may have included - physician only-based intervention rather than multidisciplinary, and intervening on chronically ill patients not otherwise referred for palliative care
	Patient symptoms; Anxiety	Scoring from 1-10				NS		
	Patient symptoms; Dyspnea	Scoring from 1-10				NS		
	Quality of care measures; Care, Preferences, Prognosis, and Spiritual Care					NS		
Rabow, 2004 ²¹	QOL	Multidimensional Quality of Life Scale—Cancer Version	90	None		NS		Most effective in improving outcomes that the team could influence directly, via provision of services, education, and support.
	Pain scores	Brief Pain Inventory				NS		
	Patient symptoms; DepressionAnxiety	CES-DProfile of Mood States				NS		
	Other	Spiritual Well-Being Scale			Improved 7.5 vs. 1.5: p=0.05			

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Rabow, 2004 ²¹ (continued)	Satisfaction	Group Health Association of America Consumer Satisfaction Survey				NS		
	Patient symptoms; Dyspnea				Reporting of any Dyspnea: OR=6.07; 95% CI= 1.04-35.56			
	Costs					NS		
	Total hospital days					NS		
Reymond, 2011 ²²	Quality of Care	Utilization	299	NR		Transfer to hospital: 12% (31253) post- vs 21.7% (1046) pre-; no statistics given		Only 47% of dying residents were placed on the pathway during the implementation period
		Satisfaction				Bereaved families evaluations of care - no significant change		
V.d. Heide, 2010 ²³			298	None		DNR agreements, options of last resort discussed		Differences in end-of-life medication use with use of the LCP

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Woo, 2011 ²⁴	Patient symptoms	Symptom checklist	169	None	Pain improved OR=0.25, CI=0.13-0.52, p<0.001	1820Symptoms =NS		Hong Kong; used PDSA, developed own care pathway and other forms; communication skills workshops in addition to extensive seminars; revision of intervention based on feedback
	QOL; Caregiver	Cost of care Index				NS		
	QOL; Patient	Mc Gill QOL Questionnaire				Not reported		
	Satisfaction; Patient (caregiver-reported)	10 point scale			7.54pre vs. 8.24 post, p=0.029			
	QOL; Caregiver	SF-12				NS		
	Service use	ER admissions, LOS, X-rays, Blood tests			Significantly less acute care admissions, LOS, X-rays, blood tests	ER admissions, Non acute care admissions		
	Satisfaction; Caregiver	10 point scale			7.8 pre vs. 8.56 post, p=0.017			
	Distress	Chinese Death Anxiety Inventory				Not reported for patients		

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Temel, 2010 ²⁵	QOL	Trial Outcome Index (TOI)-sum of scores on the Lung Cancer Subscale and the physical well-being and functional well-being subscales of the Functional Assessment of Cancer Therapy–Lung Scale	151	African American (4%), Asian (1%), Hispanic (1%)	TOI Control 53.0+ 11.5- vs. intervention 59.0 +- 11.6 (P = 0.009) 95%CI 1.5-10.4). Effect size 0.52; FACT-L and LCS also statistically significantly different		None	Average # of palliative care visits was 4;14% in control group had palliative care - all 1-2 visits; duration, 11 days in intervention group vs. 4 days in control group (P = 0.09) - insufficient sample size for statistics on other indicators, such as chemotherapy, but rates were lower in intervention group Highly-specialized academic center and advanced palliative care program.

Evidence Table 5. Outcomes reported in studies addressing continuity, coordination of care, and transitions (continued)

Author, Year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Temel, 2010 ²⁵ (continued)	Distress; Mood, patient depressive symptoms	Hospital Anxiety and Depression Scale and the Patient Health Questionnaire 9			Fewer depressive symptoms in Intervention 16% vs control 38%, (P = 0.01) on HADS-D; also statistically significant for PHQ-9			
	Health care use	Overall for those who died, all: chemo-therapy, ER visits, any admissions until death			Fewer received overall aggressive end-of-life care in intervention group 33% vs. Control 54% (P =0.05)	All: chemotherapy, ER visits, any admissions until death		
	Survival				Longer median survival in intervention group 11.6 months vs. Control 8.9 months (P = 0.02)			

Abbreviations: AD=Advanced Directives; AQEL=Assessment of Quality of life at the End of Life; CAT=Chart Abstraction Toll; CCCI=Cost of care Index ; CES-D=Center for Epidemiologic Studies Depression Scale; COPD=Chronic Obstructive Pulmonary Airway Disease; CRA=Care Giver Assessment; DNR=Do Not Resuscitate; EOL=End of Life; EORTC=European Organization for Research and Treatment of Cancer's core; ER=Emergency Room; ESAS=Edmonton Symptom assessment scale; FACT-L=Functional Assessment of Cancer Therapy–Lung; GSF=Gold Standard Framework; HADS-D=Hospital Anxiety and Depression Scale; ICU=Intensive Care Unit; LCS=Lung Cancer Scale; LOS=Length of Stay; NS=Not Significant; PHQ=Patient Health Questionnaire; PHQ-9=Patient Health Questionnaire 9; QOL=Quality of Life; SCL=Symptom Checklist; SE=Standard Error; SF=Significant Finding

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Evidence Table 6. Description of interventions for studies addressing pain

Author, year	Integrative vs. consultative
Anderson, 2004 ¹	consultative
Aubin, 2006 ²	Integrative: interacts with both
Borneman, 2008 ³	Combined: interacts with both
Borneman2010 ⁴	Integrative
Dalton, 2004 ⁵	Consultative: interacts with patientfamily
Du Pen, 2000 ⁶	Combined: interacts with both
Fuchs-Lacelle, 2008 ⁷	Integrative
Given, 2002 ⁸	Integrative: interacts with patientfamily
Keefe, 2005 ⁹	Consultative: interacts with patientfamily
Kovach 2006 30572	Combined: interacts with both
Lovell, 2010 ¹⁰	Otherneither
Marinangeli, 2004 ¹¹	Integrative
Miaskowski, 2004 ¹² , Miaskowski 2007 ¹³	Consultative: interacts with patientfamily
Oldenmenger, 2011{#40373}	consultative
Oliver, 2001 ¹⁴ ; Kalauokalani, 2007 ¹⁵	Consultative: interacts with patientfamily
Syrjala, 2008 ¹⁶	Integrative
Van der Peet, 2004 ¹⁷	Consultative: interacts with both
Ward, 2000 ¹⁸	Integrative
Ward, 2008 ¹⁹	Consultative: interacts with patientfamily
Wells, 2003 ²⁰	Combined: interacts with both
Wilkie, 2010 ²¹	Consultative: interacts with patientfamily

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Evidence Table 7. Description of quality improvement elements in studies addressing pain

Author, year	Facilitated relay of clinical data to providers?	Audit and feedback?	Provider education?	Patient family caregiver education?	Promotion of self-management?	Patient caregiver reminder system?	Organizational change?	Other?
Anderson, 2004 ¹	No	No	No	Yes	Yes	No	No	No
Aubin, 2006 ²	No	No	Yes	Yes	Yes	No	No	No
Borneman, 2008 ³	Yes	Yes	Yes	Yes	Yes	No	Yes	No
Borneman, 2010 ⁴	No	No	No	Yes	Yes	No	No	No
Dalton, 2004 ⁵	No	No	No	Yes	Yes	No	No	No
Du Pen, 2000 ⁶	No	No	Yes	No	No	No	No	No
Fuchs-Lacelle, 2008 ⁷	Yes	No	No	No	No	No	No	Yes
Given, 2002 ⁸	No	No	No	Yes	Yes	No	No	No
Keefe, 2005 ⁹	No	No	No	Yes	Yes	No	No	No
Kovach, 2006 ¹⁰	Yes	No	Yes	No	No	No	No	No
Lovell, 2010 ¹¹	No	No	No	Yes	Yes	No	No	No
Marinangeli, 2004 ¹²	Yes	No	No	No	No	No	No	No
Miaskowski, 2004 ¹³ , Miaskowski 2007 ¹⁴	Yes	No	No	Yes	Yes	No	No	No
Oldenmenger, 2011 ¹⁵	No	No	No	Yes	Yes	No	No	Yes
Oliver, 2001 ¹⁶ , Kalauokalani, 2007 ¹⁷	No	No	No	Yes	Yes	No	No	No
Syrjala, 2008 ¹⁸	No	No	No	Yes	Yes	No	No	No
Van der Peet, 2004 ¹⁹	Yes	No	No	Yes	Yes	No	No	Yes
Ward, 2000 ²⁰	No	No	No	Yes	Yes	No	No	No
Ward, 2008 ²¹	No	No	No	Yes	Yes	No	No	No
Wells, 2003 ²²	No	No	No	Yes	Yes	No	No	No
Wilkie, 2010 ²³	No	No	No	Yes	Yes	Yes	No	No

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 23. Wilkie D, Berry D, Cain K *et al.* Effects of coaching patients with lung cancer to report cancer pain. *Western Journal of Nursing Research* 2010; 32(1):23-46.

Evidence Table 8. Risk of bias assessment of studies addressing pain

Author, year	Sequence generation	Allocation concealment	Binding of personnel (short-term outcomes)	Blinding of outcome assessors (short-term outcomes)	Binding of personnel (long-term outcomes)	Blinding of outcome assessors (long-term outcomes)	Incomplete outcome data (short-term outcomes)	Incomplete outcome data (long-term outcomes)	Selective outcome reporting	Other sources of bias
Anderson, 2004 ¹	Unclear	Unclear	No	No	No	No	Yes	Yes	Yes	Yes
Aubin, 2006 ²	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Borneman, 2008 ³	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Borneman 2010{741}	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Dalton, 2004 ⁴	Unclear	Unclear	No	No	No	No	Yes	Yes	Yes	Yes
Du Pen, 2000 ⁵	Unclear	No	No	No	No	No	Yes	No	No	No
Given, 2002 ⁶	Unclear	No	No	No	No	No	No	No	No	No
Keefe, 2005 ⁷	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Kovach, 2006 ⁸	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lovell, 2010 ⁹	Unclear	Yes	No	Unclear	No	No	Yes	Unclear	Unclear	Yes
Marinangeli, 2004 ¹⁰	Unclear	Unclear	No	No	No	No	Yes	Yes	Yes	Yes
Miaskowski, 2004 ¹¹	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Miaskowski, 2007 ¹²	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Oldenmenger, 2011 ¹³	Yes	Unclear	No	Yes	No	Yes	Yes	Yes	Yes	Yes
Oliver, 2001 ¹⁴ , Kalauokalani, 2007 ¹⁵	Unclear	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes
Syrjala, 2008 ¹⁶	Unclear	No	No	No	No	No	No	No	No	No
Van der Peet, 2004 ¹⁷	Yes	Yes	No	No	No	Yes	Yes	Yes	Yes	Yes
Ward, 2000 ¹⁸	Unclear	No	No	No	No	No	No	No	No	No
Ward, 2008 ¹⁹	Unclear	No	No	No	No	No	Yes	Yes	No	No
Wells, 2003 ²⁰	Unclear	No	No	No	No	No	No	No	No	No
Wilkie, 2010 ²¹	Yes	Yes	No	No	No	No	Yes	Yes	Yes	Yes

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Evidence Table 9. Outcomes reported in studies addressing pain

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Anderson, 2004 ¹	pain (intensity and interference)	BPI	97	specifically looking at underserved populations (black and hispanic only)		NS	At the 8-10 week assessment only (of 3 different assessment time points), the control group reported a lower mean pain worst rating than the education group ($P = .05$) AA Patients only: analysis of the pain worst item revealed a significant group-by-time interaction ($P < .01$). For pain interference: significant group-by-time interaction for the African American patients ($P < .04$) but not for Hispanic patients ($P = .41$); recruitment was challenging in this population
	QOL	Physical and Mental Health Summary Scales of the Short Form (SF) -12 Health Survey				NS	

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Aubin, 2006 ²	Pain scores	BPI	80 patients, control: 27, intervention: 53		Average pain scores at baseline, two weeks and four weeks between the experimental (3.0, 2.1, 1.7) and control groups (2.4, 3.3, 2.4) were significantly different (p = 0.01)	Maximum pain scores were not significantly different over time for the experimental and control groups	
Borneman, 2008 ³	Pain scores	QOL scalecancer patient tool,	46 patients, 18 in control, 28 in intervention		No statistically significant effects on outcomes of interest between experimental and control	Overall QOL, physical QOL, psychological QOL, spiritual QOL, social QOL, fatigue-related QOL, pain-related QOL all ns	
	Fatigue	Piper fatigue scale				Sensory fatigue, overall fatigue	
Borneman, 2010 ⁴	Pain scores	Treatment data	187 patients, 83 in control; 104 in intervention	Sample included 35% ethnic minorities		NS	
	Fatigue	Piper fatigue scale, barriers questionnaire, fatigue barriers scale, fatigue knowledge tool			Sensory fatigue dropped significantly at one and three months for the intervention group (baseline: 6.4; 1 month: 5.4; 3 months: 4.4), it did not change over time for the usual care group (baseline: 6.4; 1 month: 6.2; 3 months: 5.5), and this difference was statistically significant (p=0.025)		

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Dalton, 2004 ^b	Pain scores	BPI	127 patients, standard cbt=43, profile tailored cbt (intervention) = 50, usual care = 34			6 month follow-up: of 10 components of BPI, only 1 statistically significant in each arm vs. usual care at p=0.04	High level of attrition; unable to abstract 1-month outcomes from study due to table formatting issue, despite contact with authors
	Distress	Symptom distress scale			6 months: 36 symptoms statistically significant for tailored intervention		
	Psychosocial symptoms	Profile of mood states				6 months: ns for tailored, 12 significant for standard	
	QOL	Sf-12				6 months: ns	
	Karnofsky performance status, pain goals					Ns	
Du pen, 2000 ⁶	Pain scores	BPI	20 oncologists and 38 oncology nurses; 105 patients - 54 in intervention, 51 in control		Intervention group experienced a decrease in their mean level of usual pain on a scale of 0 to 10 from a baseline mean score of 3.6 (standard deviation [sd] =1.9) to a mean score of 2.8 (sd =1.9); patients treated by untrained physicians nurses experienced a relatively flat trajectory in their level of usual pain over the 4 months of their treatment (mean =3.0, sd =2.0). The difference between the 2 groups was statistically significant(t = 2.0, p = .05)		

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Du pen, 2000 ⁶ (continued)	Opioid provider adherence scores (0 to 3 scale), neuropathic co-analgesic prescribing	Chart abstraction				NS	
	Overall adherence	Chart abstraction - aggregate score (tpa)			Statistically significant improvement in tpa in the trained group versus control group, as measured by slope scores (t = 2.1, p = .04).		
Fuchs-lacelle, 2008 ⁷	Nurse-assessed pain scores	Pain assessment checklist for seniors with limited ability to communicate	173, 89 in intervention, 84 in control			Longitudinal outcome: systematic pain assessment statistically changed the log expected rate of observable pain behaviors. More specifically, pain scores, as measured by the pacslac, showed a statistically significant decrease at the rate of 0.01 for each unit of time.	

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Fuchs-lacelle, 2008 ⁷ (continued)	Increased use of underused pain management medication	(medication quantification scale)				Longitudinal outcome: baseline (0.64, sd=2.07) for the experimental condition and (0.44, sd=1.65) for the control condition. At the end of the intervention, (0.98 (sd=2.12) for the experimental condition and (0.16, sd=0.82) for the control condition. (p=0.00)	
Given, 2002 ⁸	Pain scores	The symptom experience scale	113 patients 53 in intervention, 60 in control			Ns	
	Fatigue	The symptom experience scale				Ns	
Keefe, 2005 ⁹	Pain scores	BPI - usual pain and worst pain	78 patients, 41 in intervention, 37 in control i			Ns	
	QOL,, caregiver strain, caregiver mood,					Ns	
Kovach, 2006 ¹⁰	Patient symptoms; discomfort	Behave-ad	114 patients; 57 each in intervention and control			Ns	
		Discomfort-data			Significant intervention x time effect on discomfort-ad scores (p<0.001)		

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Lovell, 2010 ¹¹	Pain scores	Wisconsin brief pain inventory	185 patients, 40 in standard care, 37 in booklet only group, 36 in video only group, 45 in booklet plus video group		There was a significant difference in the change in average pain score between the standard care group (mean: 0.02) and the booklet and video group (mean: 1.19; difference: 1.17 with 95% ci: 0.17, 2.17, p = 0.0214). Reductions in worst pain scores were significantly greater in the booklet and video group than in the standard care group (1.53 vs. 0.41; difference: 1.12 with 95% CI: 0.00, 2.23, p = 0.05).	Booklet versus standard care ns video versus standard care ns no significant differences for pain interference between the groups	There were marginal differences between standard care and booklet alone (p = 0.07) and standard care and video alone (p = 0.09) for average pain the presence of a partner increased the effect of any educational intervention on average pain and worst pain scores compared to those without partners (significant)
Lovell, 2010 ¹¹	Anxietydepression, QOL	Hospital anxiety and depression scale, uni-scale for global quality of life				Ns	
Marinangeli, 2004 ¹²	Pain scores	Vas	92 patients, 44 in intervention, 48 in control		Intervention group significantly better than control group on pain scores (control - 4.98 +- 1.26 vs. Intervention 4.23 +- 1.36; p 0.007) and with greater decrease in pain from baseline (intervention -2.61, control -1.92, p=0.041).		

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Marinangeli, 2004 ¹² (continued)	QOL, performance status	Multidimensional questionnaire. Karnovsky performance status				NS	
	Side effects				Nausea as a side effect was significantly lower in the intervention group (315 episodes versus 437 episodes; $p = 0.0001$).	Vomiting, constipation, gastro-enteric bleeding, periods of mental confusion	
	Satisfaction				Intervention group significantly more satisfied with pain management (intervention 85.6% vs. Control 80.5%, $p = 0.041$).		
Miaskowski, 2004 ¹³ and Miaskowski, 2007 ¹⁴	Pain scores; pain intensity	BPI	174 patients, intervention=93, control=81 (2004), 167; intervention=89, control=78 (2007)		For least pain, a significant group x time interaction ($p < 0.0001$) was found. For average pain, a significant group x time interaction ($p < 0.0001$) and significant main effects by group ($p = 0.026$) for worst pain, a significant group x time interaction ($p < 0.0001$) as well as significant main effects of group ($p = .033$) were found.	No significant difference for least pain scores between groups.	
	Pain interference	BPI				Ns	

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Miaskowski, 2004 ¹³ and Miaskowski, 2007 ¹⁴ (continued)	Opioid intake, appropriate analgesia, mood state QOL	Nurse recorded analgesic intake and prescriptions, profile of mood states				Ns	
		SF-36			Only significant difference is on subscale for body pain, intervention = 39.6, control=46.8 (p=0.005)		
Oliver, 2001 ¹⁵ Kalauokalani, 2007 ¹⁶	Pain scores; average pain	BPI	67 patients, 34 in intervention, 33 in control		Controlling for pain at baseline average pain differed by -8.96 points on a 100 point scale between control and experimental groups (p<0.05)	When social factors are added to the model, this association fails to meet significance	
	Impairment due to pain and pain frequency	Pain effects subscale of the mos-paq				Functional impairment due to pain and pain frequency - no significant differences	

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Oldenmenger, 2011 ¹⁷	Pain intensity	BPI (current, average, and worst in past 24 hours)	72		For average pain intensity, the mean difference in pain intensity (mDPI) was 1.13 for SC and 1.95 for PC-PEP (20% vs 31%; P = .03). For current pain intensity, the mDPI was 0.67 for SC and 1.50 for PC-PEP (16% vs 30%; P = .016).	No significant difference was found between SC and PC-PEP groups for worst pain (1.16 vs 1.28).	Higher adherence to analgesics in intervention group (p=0.03); results were sustained over study period; most patients had multiple visits with pain consult service
	Pain interference	BPI interference questions (7 items, averaged)			For daily interference, the mean reduction was 0.11 for SC and 0.91 for PC-PEP (2.5% vs 20%; P = .01)		
	Pain knowledge	Ferrell Patient Pain Questionnaire			At week 2, the level of pain knowledge (0 to 100) was significantly better after randomization to PC-PEP (71, SD = 13) than to SC (64,SD=10;P=.002)		
	adequacy of analgesia	PMI (Pain Management Index)					

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Oliver, 2001 ¹⁵ Kalaoukalani, 2007 ¹⁶ (continued)			Minority patients: 8 in intervention, 7 in control	Regression analysis, adjusting for baseline pain, revealed a significant interaction between minority status (Latinos, Asians, blacks, other) and study group for BPI, indicating a greater effect of the intervention in minorities (interaction effect = -1.73, 95% ci = -0.06, -3.41, p = 0.043);			

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Syrjala, 2008 ¹⁸	Pain scores	BPI	78 patients, 43 in intervention, 35 in control		Intervention group with better control of usual pain - differed by -.81 with intervention group having greater decrease in pain from baseline (p=0.03))	Group comparisons were not significant at 6-month time point.	
	Increased use of opioids	Patient interview and viewing medications by research nurses			Significant difference in opioid dose between intervention and control group (<0.001) with intervention group taking more morphine (0.31 in log10 of daily morphine dose)		The pain training effect on opioid use differed significantly, also, between those whose pain was due to treatment versus those whose pain was due to other etiology, primarily due to disease (p = .009)
	Patient symptoms	Memorial symptom assessment scale				NS	
Van der peet, 2004 ¹⁹	Pain scores	BPI	120 patients, 58 in intervention, 62 in control		Present pain score intervention group = 3.78 versus control group = 4.84 (p=0.02) at 4 weeks follow up	Difference between intervention and control group ns at 8 weeks follow up	Patients in the most pain (BPI -7 or higher) had the greatest benefit from the intervention - significant differences in pain were found between the intervention and control groups at t1 (p=0.00) and t2 (p=0.00) in patients with a baseline score of 7–10.

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Van der peet, 2004 ¹⁹	Depression anxiety; Quality of Life, and non-pain symptoms	HADS				Not reported	
Ward, 2000 ²⁰	Pain scores; pain intensity	BPI	43 patients, 21 in intervention, 22 in control			NS	
	Pain scores; pain interference	BPI interference scale, plus one additional item about caring for others				NS	
	Analgesic side effects scores, adequacy of analgesia, QOL	Medication side effect checklist. PMI, fact-g				NS	
Ward, 2008 ²¹	Pain scores; pain severity	BPI - worst, least, and pain now - aggregated to single score, also used one question from the total pain management quality dataset for "usual severity"	176 total patients, 92 in intervention, 84 in control			NS	
	Pain interference, analgesic use, QOL	BPI				NS	

Evidence Table 9. Outcomes reported in studies addressing pain (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: benefits. Significantly improved	Outcomes: benefits. Not significantly improved	Other key information
Wells, 2003 ²²	Pain scores; worst pain, average pain, pain interference, pain relief	BPI-SF	64 patients, 24 in standard care, 21 in hot line intervention, and 19 in weekly call intervention			NS	
	Analgesic use	PMI				NS	
Wilkie, 2010 ²³	Pain scores	Mcgill pain questionnaire,	151 patients, 76 in intervention, 75 in control			NS except for 1 subscale	This intervention did statistically significantly improve pain communication by patients to providers (audio taped data): intervention improved reporting, but more than this is needed to change provider and patient behavior and improve pain
	Anxiety, depression, pain coping, pain prescriptions	State trait anxiety inventory, CES-D coping strategies questionnaire, PMI				NS	

Abbreviations: BPI=Blood Pressure Index; MQS=Michigan Quality System; PMI=Pain Management Index; QOL=Quality of Life; SF=Significant Finding; HADS=The Hospital Anxiety and Depression Scale; NS=Not Significant;

Evidence Table 9 Reference List

1. Anderson KO, Mendoza TR, Payne R *et al.* Pain education for underserved minority cancer patients: a randomized controlled trial. *J Clin Oncol* 2004; 22(24):4918-25.
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Evidence Table 10. Description of interventions for studies addressing distress

Author, year	Integrative vs. consultative	Target of intervention
Aranda, 2006 ¹	Combined: interacts with both	Psychosocial needs
Blumenthal, 2006 ²	Consultative: interacts with family	Distress, coping
Carlson, 2010 ³	Consultative: interacts with family	Distress, depression, anxiety
Hudson, 2005 ⁴	Consultative: interacts with family	Support for family
Porter, 2011 ⁵	Consultative: interacts with patientfamily	Patient pain, psychological distress, quality of life measure, and self-efficacy. Caregiver mood, strain, and self-efficacy in symptom management.
Steel, 2007 ⁶	Consultative: interacts with patientfamily	Interdisciplinary assessments
Walsh, 2007 ⁷	Consultative: interacts with patientfamily	Care giver distress, needs

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Evidence Table 11. Description of quality improvement elements in studies addressing distress

Author, year	Facilitated relay of clinical data to providers?	Provider education?	Patient family caregiver education?	Promotion of self-management?	Patient caregiver reminder system?	Organizational change?	Other?
Aranda, 2006 ¹	Yes	Yes	Yes	Yes	No	No	No
Blumenthal, 2006 ²	No	No	Yes	Yes	No	No	No
Carlson, 2010 ³	No	No	No	No	No	Yes	No
Hudson, 2005 ⁴	No	No	Yes	Yes	Yes	No	No
Porter, 2011 ⁵	No	No	Yes	Yes	No	No	No
Steel, 2007 ⁶	No	No	Yes	Yes	No	No	Yes
Walsh, 2007 ⁷	No	No	Yes	Yes	No	No	No

Evidence Table 11 Reference List

1. Aranda S, Schofield P, Weih L, Milne D, Yates P, Faulkner R. Meeting the support and information needs of women with advanced breast cancer: a randomized controlled trial. *Br J Cancer* 2006; 95(6):667-73.
2. Blumenthal JA, Babyak MA, Keefe FJ *et al*. Telephone-based coping skills training for patients awaiting lung transplantation. *Journal of Consulting and Clinical Psychology* 2006; 74(3):535-44.
3. Carlson LE, Groff SL, Maciejewski O, Bultz BD. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clinical Oncology* 2010; 28(33):4884-91.
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5. Porter LS, Keefe FJ, Garst J *et al*. Caregiver-Assisted Coping Skills Training for Lung Cancer: Results of a Randomized Clinical Trial. *J Pain Symptom Manage* 2010.
6. Steel JL, Nadeau K, Olek M, Carr BI. Preliminary results of an individually tailored psychosocial intervention for patients with advanced hepatobiliary carcinoma. *J Psychosocial Oncology* 2007; 25(3):19-42.
7. Walsh K, Jones L, Tookman A *et al*. Reducing emotional distress in people caring for patients receiving specialist palliative care. Randomized trial. *Br J Psychiatry* 2007; 190:142-7.

Evidence Table 12. Risk of bias assessment of studies addressing distress

Author, year	Sequence generation	Allocation concealment	Binding of personnel (short-term outcomes)	Blinding of outcome assessors (short-term outcomes)	Binding of personnel (long-term outcomes)	Blinding of outcome assessors (long-term outcomes)	Incomplete outcome data (short-term outcomes)	Incomplete outcome data (long-term outcomes)	Selective outcome reporting	Other sources of bias
Aranda, 2006 ¹	Yes	Yes	Unclear	Unclear	Unclear	Unclear	Yes	Yes	Yes	Yes
Blumenthal, 2006 ²	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes
Carlson, 2010 ³	Yes	Yes	Yes	Unclear	Yes	Unclear	Yes	Yes	Yes	Yes
Hudson, 2005 ⁴	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Porter, 2011 ⁵	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Steel, 2007 ⁶	Unclear	Unclear	No	Yes	No	Yes	Yes	Yes	Yes	Yes
Walsh, 2007 ⁷	Yes	Yes	No	No	No	No	Yes	Yes	Yes	Yes

Evidence Table 12 Reference List

1. Aranda S, Schofield P, Weih L, Milne D, Yates P, Faulkner R. Meeting the support and information needs of women with advanced breast cancer: a randomized controlled trial. *Br J Cancer* 2006; 95(6):667-73.
2. Blumenthal JA, Babyak MA, Keefe FJ *et al*. Telephone-based coping skills training for patients awaiting lung transplantation. *Journal of Consulting and Clinical Psychology* 2006; 74(3):535-44.
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7. Walsh K, Jones L, Tookman A *et al*. Reducing emotional distress in people caring for patients receiving specialist palliative care. Randomized trial. *Br J Psychiatry* 2007; 190:142-7.

Evidence Table 13. Outcomes reported in studies addressing distress

AuthorYear Refid	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Carlson, 2010 ¹	Distress; Impact of referrals	Minimal Distress thermometer; Full Psychological Scan for Cancer (Triage (full screen and offered referral to psychosocial services))	1134	Canadian; White; European; Asian; First Nations; African; Arabic; CentralSouth American	All patients: Triage group lower distress than minimal group (p=0.031); Over distress cutoff (DT score>=4): 36% in triage, 46% full screen, 48.7% in minimal screen (X ² =10.55, p=0.005)	All patients: overall lower distress at follow-up (F=2.37, p=0.094)	All patients: Referral linked to less improvement on DT (t=4.43, p<0.001); higher baseline stress predicted greater decrease on DT (t=-3.69, p<0.001); High baseline distress improved more if lower levels of education (t=2.05, p=0.041) and without chemo (t=2.16, p=0.031)	Distress scores in breast lower at follow- up in full and triage groups. Triage group in lung with high baseline distress showed 20% reduction in distress at follow-up showing benefit of psycho social intervention.

Evidence Table 13. Outcomes reported in studies addressing distress (continued)

AuthorYear Refid	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Carlson, 2010 ¹ (continued)	Psychosocial symptoms and support				Lung: DT scores: No change; Over distress cutoff: 30.7% triage, 50.9% full screen, 51.3% minimal screen ($X^2=14.51$ $p=0.001$)	Men with higher baseline depression improved more than women ($t=1.97$, $p=0.047$)	Higher baseline anxiety levels predicted greater improvement ($t=-4.91$, $p<0.016$); higher anxiety in lung improved more than higher anxiety in breast ($t=2.68$, $p=0.008$); higher anxiety among those receiving hormone therapy improved less than those who did not ($t=-2.60$, $p=0.01$)	Referral to psychosocial resources improved anxiety and depression but DT scores were higher.
	Other				Breast: Study condition associated with DT scores ($F=3.27$, $p=0.039$); Triage and full screen had lower DT scores than minimal screen ($p<0.05$)		Predictor of depression (PSSCAN depression) improvement: Greater baseline depression ($t=-4.72$, $p<0.001$)	Study highly feasible; 90% recruitment and 84.47% (breast) and 64.7% (lung) retention.

Evidence Table 13. Outcomes reported in studies addressing distress (continued)

AuthorYear Refid	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Carlson, 2010 ¹ (continued)					No difference in anxiety and depression scores at follow-up			
					Predictor of depression improvement: referral (t=2.229, p=0.03); lower income (t=2.01, p=0.036) and lower income with higher baseline depression (t=3.48, p=0.001); male (t=2.14, p=0.033) and male with higher baseline depression (t=1.97, p=0.047)			
Walsh, 2007 ²	Distress; Bereavement	General Health Questionnaire	271	14% non-white (not further stratified)	None	Reduction in career distress	Quality of life decreased over time in both arms	Need larger sample size and longer, ongoing intervention.
	QOL							
	Satisfaction							
	Other							

Evidence Table 13. Outcomes reported in studies addressing distress (continued)

AuthorYear Refid	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Aranda, 2006 ³	Psychosocial symptoms and support	EORTC QLQ-30	105	Not reported		NS on any of 5 scales		For group with lower baseline needs only: 19-point vs. 14-point decrease in psychological needs in intervention group vs. Control (p=0.026) Need larger sample size and greater follow-up time and subsequent intervention sessions.
	Needs	Supportive care needs survey				NS		
Blumenthal, 2006 ⁴	Depression	Beck Depression Inventory	328	Mostly Caucasian pop	11.1 to 9.8 vs. 12.6 to 8.8 (treatment), p=0.003		No harms listed	CST was effective for pts with poor PQOL at beginning of treatment but little difference if PQOL was good already at beg of treatment
	Distress	General Health Questionnaire			45.2 to 43.2 vs. 48.1 to 39.7 (treatment), p=0.035			
	Anxiety	State-Trait Anxiety Inventory-State Form			36.1 to 35.0 vs. 38.1 to 33.9 (treatment), p=0.045			
	QOL	Pulmonary- Specific Quality of Life Scale PQLS				NS		

Evidence Table 13. Outcomes reported in studies addressing distress (continued)

AuthorYear Refid	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Blumenthal, 2006 ⁴ (continued)	Secondary listed as stress, mental health, social support, vitality and optimism; also SF-36 somatic outcomes and survival	SF-36				No differences in somatic QOL outcomes or survival		
Hudson, 2005 ⁵	Psychosocial symptoms and support	HADS	106	Not addressed other than 74.3% Australian born and 74.3% identified as Christians		NS		Assessment tools not validated previously for this population
	Rewards	Rewards of care giving Scale			P=0.036	Time 1-Time 2 not sig but Time to Time 3 sig		Only 15 standard care participants and 12 intervention participants completed assessments at all three time points
		Preparedness for Care giving Scale				NS		Caregivers in this study were highly functioning making it difficult to improve intervention effects
								The impact of participants' pre palliative care characteristics on the success of the intervention remains unknown

Evidence Table 13. Outcomes reported in studies addressing distress (continued)

AuthorYear Refid	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Hudson, 2005 ⁵ (continued)		Caregiver Competence Scale				NS		Gate keeping at access was a potential influence on sample representativeness
								A set of questions specific to the intervention aims and tested within the study might have assisted interpretation of the results
Porter, 2011 ⁶	QOL; three way dichotomizing patient's and caregivers based on	For patients-pain Basic Pain Inventory Scale, distress-Beck Depression Inventory	233	11% African American		No outcomes significantly improved over time	None	No control group with no intervention
	Satisfaction; cancer stage of I, II or III	Anxiety-State trait anxiety inventory						Future studies could include using a stepped approach, early stage pts could benefit from shorter interventions, design future study to examine efficacy of various interventions
	Pain scores	Self efficacy- used some questions from the chronic pain self efficacy scale						Only 54% of pts asked choose to participate

Evidence Table 13. Outcomes reported in studies addressing distress (continued)

AuthorYear Refid	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Porter, 2011 ⁶ (continued)		QOL-Functional Assessment of Cancer therapy lung cancer						Attrition rate at 27% post test and 40% at four month mostly due to deaths
								Pts predominantly Caucasian
		For caregivers- caregiver mood- Profile of Mood States-B						
		Caregiver strain- Caregiver Strain Index						
		Caregiver self efficacy in symptom management- used modified version of self efficacy scale as patients used						

Evidence Table 13. Outcomes reported in studies addressing distress (continued)

AuthorYear Refid	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Steel, 2007 ⁷	QOL	Functional Assessment of Cancer Therapy- Hepatobiliary	28	African American (1), Native American (1) HispanicLatino (2) Other? (1)		QOL via FACT- did not use p values to describe	None	Looked at mean change in scores during assessment times for analysis
	Anxiety	State Trait Anxiety Index				Reported decrease in anxiety from beginning assessment to end assessment comparing control group and intervention group	None	Need further research with a larger sample size (this is underway)
	Other	Center for Epidemiological Studies- Depression Scale				Reported reduction in depressive symptoms between control and intervention group between beg and end assessment	None	Although difference bet control and intervention group was not statistically significant, they were clinically significant.
	Other	Date of diagnosis to death				Intervention group had longer survival by 20days but not statistically significant	None	
								Other QI - structured patient assessment and intervention;

Abbreviations: CCS=Care giver Competence Scale; CES-D=Center for Epidemiological Studies-Depression Scale ; DT=Minimal Distress thermometer ; FACT-Hep=Functional Assessment of Cancer Therapy-Hepatobiliary ; GHQ=General Health Questionnaire; HADS=Hospital Anxiety and Depression Scale; NS=Not Significant; PQOL=Patient Recorded Outcome and Quality of Life Scale; PSSCAN=Full Psychological Scan for Cancer ; QI=QMCI; Pain Tracking Tool; QOL=Quality of Life; STAI=State Trait Anxiety Index

Evidence Table 13 Reference List

1. Carlson LE, Groff SL, Maciejewski O, Bultz BD. Screening for distress in lung and breast cancer outpatients: a randomized controlled trial. *J Clinical Oncology* 2010; 28(33):4884-91.
2. Walsh K, Jones L, Tookman A *et al.* Reducing emotional distress in people caring for patients receiving specialist palliative care. Randomized trial. *Br J Psychiatry* 2007; 190:142-7.
3. Aranda S, Schofield P, Weih L, Milne D, Yates P, Faulkner R. Meeting the support and information needs of women with advanced breast cancer: a randomized controlled trial. *Br J Cancer* 2006; 95(6):667-73.
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5. Hudson PL, Aranda S, Hayman-White K. A psycho-educational intervention for family caregivers of patients receiving palliative care: a randomized controlled trial. *J Pain Symptom Manage* 2005; 30(4):329-41.
6. Porter LS, Keefe FJ, Garst J *et al.* Caregiver-Assisted Coping Skills Training for Lung Cancer: Results of a Randomized Clinical Trial. *J Pain Symptom Manage* 2010.
7. Steel JL, Nadeau K, Olek M, Carr BI. Preliminary results of an individually tailored psychosocial intervention for patients with advanced hepatobiliary carcinoma. *J Psychosocial Oncology* 2007; 25(3):19-42.

Evidence Table 14. Description of interventions for studies addressing communication

Author, year	Integrative vs. consultative	Target of intervention
Ahrens, 2003 ¹	Combined: interacts with both	Communication
Campbell, 2003 ²	Consultative: interacts with both	Communication
Clayton, 2007 ³	Integrative	Patient participation during oncology consultations, psychosocial support.
Cowan, 2003 ⁴	Consultative: interacts with both	Provider-patient family communication, information giving, understanding and making decisions with families.
Gade, 2008 ⁵	Consultative: interacts with both	Interdisciplinary teams, symptom management, psychosocial and spiritual support, end-of-life planning, and post-hospital care.
Hanks, 2002 ⁶	Consultative: interacts with both	Interdisciplinary teams, patients symptoms control and quality of life
Jacobsen, 2011 ⁷	Integrative	Interdisciplinary teams, advance care planning, provider-patient communication
Kaufer, 2008 ⁸	Consultative: interacts with both	Provider-patient family communication, decision making, quality of care, family satisfaction and minority patient population
Lautrette, 2007 ⁹	Combined: interacts with provider	Patient family and providers
Lilly, 2000 ¹⁰	Integrative	Interdisciplinary teams, patients goals and expectations of care, critical care use and advanced supportive technology
Lilly, 2003 ¹¹	Integrative	Dying patients directed care goals, patients and family centered care plan, interdisciplinary team
Molloy, 2000 ¹²	Integrative	Advance care planning, patient and provider education, decision making
Mosenthal, 2008 ¹³	Combined: interacts with patient/family	Prognosis, advance directives, family needs, family support, and surrogate decision maker, and pain and symptoms
Muir, 2010 ¹⁴	Integrative	Provider-patient family communication and decision making.
Norton, 2007 ¹⁵	Consultative: interacts with both	Provider-patient communication, decision making on goals of care and potential treatment limitations.
Penticuff, 2005 ¹⁶	Integrative	Care planning, parent -professional collaboration
Sampson, 2011 ¹⁷	Mixed	Advance care planning, provider and carer communication, carer distress, patients pain and distress
Schneiderman, 2000 ¹⁸	Consultative: interacts with both	Interdisciplinary teams, ethical issues: cardiopulmonary resuscitation; do-not-attempt resuscitation; tracheotomy, gastrostomy, and transfusion; artificial nutrition/hydration, and ventilation.
Schneiderman, 2003 ¹⁹	Consultative: interacts with both	Provider-patient and family communication (sharing information, dealing with emotional discomfort and grieving, correcting misunderstandings)
Tulsky, 2011 ²⁰	integrative	Provider education, patient centered care, and provider-patient communication.

Evidence Table 14 Reference List

1. Ahrens T, Yancey V, Kollef M. Improving family communications at the end of life: implications for length of stay in the intensive care unit and resource use. *Am J Crit Care* 2003; 12(4):317-23; discussion 324.
2. Campbell ML, Guzman JA. Impact of a proactive approach to improve end-of-life care in a medical ICU. *Chest* 2003; 123(1):266-71.
3. Clayton JM, Butow PN, Tattersall MH *et al.* Randomized controlled trial of a prompt list to help advanced cancer patients and their caregivers to ask questions about prognosis and end-of-life care. *J Clin Oncol* 2007; 25(6):715-23.
4. Cowan JD, Burns D, Palmer TW, Scott J, Feeback E. A palliative medicine program in a community setting: 12 points from the first 12 months. *Am J Hosp Palliat Care* 2003; 20(6):415-33.
5. Gade G, Venohr I, Conner D *et al.* Impact of an inpatient palliative care team: a randomized control trial. *J Palliat Med* 2008; 11(2):180-90.
6. Hanks GW, Robbins M, Sharp D *et al.* The imPaCT study: a randomised controlled trial to evaluate a hospital palliative care team. *British Journal of Cancer* 2002; 87(7):733-9.
7. Jacobsen Juliet, Robinson Ellen, Jackson VA, Meigs JB, Billings J Andrew. Development of a Cognitive Model for Advance Care Planning Discussions: Results From a Quality Improvement Initiative. *Journal of Palliative Medicine* - 201103; 14(3): 331, 336.
8. Kaufer M, Murphy P, Barker K, Mosenthal A. Family satisfaction following the death of a loved one in an inner city MICU. *Am J Hosp Palliat Care* 2008; 25(4):318-25.
9. Lautrette A, Darmon M, Megarbane B *et al.* A communication strategy and brochure for relatives of patients dying in the ICU. *N Engl J Med* 2007; 356(5):469-78.
10. Lilly CM, De Meo DL, Sonna LA *et al.* An intensive communication intervention for the critically ill. *Am J Med* 2000; 109(6):469-75.
11. Lilly CM, Sonna LA, Haley KJ, Massaro AF. Intensive communication: four-year follow-up from a clinical practice study. *Crit Care Med* 2003; 31(5 Suppl):S394-9.
12. Molloy DW, Guyatt GH, Russo R *et al.* Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. *JAMA* 2000; 283(11):1437-44.
13. Mosenthal AC, Murphy PA, Barker LK, Lavery R, Retano A, Livingston DH. Changing the culture around end-of-life care in the trauma intensive care unit. *J Trauma* 2008; 64(6):1587-93.
14. Muir JC, Daly F, Davis MS *et al.* Integrating palliative care into the outpatient, private practice oncology setting. *J Pain Symptom Manage* 2010; 40(1):126-35.
15. Norton SA, Hogan LA, Holloway RG, Temkin-Greener H, Buckley MJ, Quill TE. Proactive palliative care in the medical intensive care unit: effects on length of stay for selected high-risk patients. *Crit Care Med* 2007; 35(6):1530-5.
16. Ritchie L. Planning end-of-life care. *Nurs N Z* 2011; 17(9):23.
17. Sampson EL, Jones L, Thune-Boyle IC *et al.* Palliative assessment and advance care planning in severe dementia: an exploratory randomized controlled trial of a complex intervention. *Palliat Med* 2011; 25(3):197-209.
18. Schneiderman LJ, Gilmer T, Teetzel HD. Impact of ethics consultations in the intensive care setting: a randomized, controlled trial. *Crit Care Med* 2000; 28(12):3920-4.
19. Schneiderman LJ, Gilmer T, Teetzel HD *et al.* Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. *JAMA* 2003; 290(9):1166-72.
20. Tulsky J, Arnold R, Alexander S *et al.* Enhancing communication between oncologists and patients with a computer-based training program: a randomized trial. *Annals of Internal Medicine* 2011; 155(9):593-601.

Evidence Table 15. Description of quality improvement elements in studies addressing communication

Author, year	Provider reminder system?	Facilitated relay of clinical data to providers?	Audit and feedback?	Provider education?	Coaching collaborative skills training?	Patient family caregiver education?	Promotion of self-management?	Patient Caregiver reminder system?	Organizational change?	Other?
Ahrens, 2003 ¹	No	Yes	No	Yes	No	No	No	No	No	No
Campbell, 2003 ²	Yes	Yes	No	No	Yes	Yes	No	No	Yes	No
Clayton, 2007 ³	No	Yes	No	No	No	Yes	Yes	No	No	No
Cowan, 2003 ⁴	No	Yes	Yes	No	No	Yes	Yes	No	No	No
Gade, 2008 ⁵	No	Yes	Yes	No	No	Yes	Yes	No	Yes	No
Hanks, 2002 ⁶	No	Yes	No	No	No	Yes	Yes	Yes	No	No
Jacobsen, 2011 ⁷	No	No	No	Yes	Yes	Yes	Yes	No	No	No
Kaufer, 2008 ⁸	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No
Lautrette, 2007 ⁹	No	No	No	Yes	Yes	Yes	No	No	No	No
Lilly, 2000 ¹⁰	No	Yes	No	No	No	Yes	Yes	No	No	No
Lilly, 2003 ¹¹	No	No	No	No	No	Yes	Yes	No	No	No
Molloy, 2000 ¹²	No	No	No	Yes	Yes	Yes	Yes	No	No	No
Mosen-thal, 2008 ¹³	No	No	No	No	No	Yes	Yes	No	No	No
Muir, 2010 ¹⁴	No	Yes	Yes	Yes	Yes	Yes	Yes	No	No	No
Norton, 2007 ¹⁵	No	Yes	Yes	No	No	Yes	Yes	No	No	No
Penticuff, 2005 ¹⁶	No	No	No	Yes	No	Yes	Yes	No	No	Yes

Evidence Table 15. Description of quality improvement elements in studies addressing communication (continued)

Author, year	Provider reminder system?	Facilitated relay of clinical data to providers?	Audit and feedback?	Provider education?	Coaching collaborative skills training?	Patient family caregiver education?	Promotion of self-management?	Patient Caregiver reminder system?	Organizational change?	Other?
Sampson, 2011 ¹⁷	No	No	No	No	No	Yes	Yes	No	No	No
Schneiderman, 2000 ¹⁸	No	Yes	No	Yes	Yes	Yes	Yes	No	No	No
Schneiderman, 2003 ¹⁹	No	Yes	No	Yes	Yes	Yes	Yes	No	No	No
Tulsky, 2011 ²⁰	No	No	Yes	Yes	No	No	No	No	No	No

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- Hanks GW, Robbins M, Sharp D *et al.* The imPaCT study: a randomised controlled trial to evaluate a hospital palliative care team. *British Journal of Cancer* 2002; 87(7):733-9.
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- Kaufer M, Murphy P, Barker K, Mosenthal A. Family satisfaction following the death of a loved one in an inner city MICU. *Am J Hosp Palliat Care* 2008; 25(4):318-25.
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19. Schneiderman LJ, Gilmer T, Teetzel HD *et al.* Effect of ethics consultations on nonbeneficial life-sustaining treatments in the intensive care setting: a randomized controlled trial. *JAMA* 2003; 290(9):1166-72.
20. Tulskey J, Arnold R, Alexander S *et al.* Enhancing communication between oncologists and patients with a computer-based training program: a randomized trial. *Annals of Internal Medicine* 2011; 155(9):593-601.

Evidence Table 16. Risk of bias assessment of studies addressing communication

Author, year	Sequence generation	Allocation concealment	Binding of personnel (short-term outcomes)	Blinding of outcome assessors (short-term outcomes)	Binding of personnel (long-term outcomes)	Blinding of outcome assessors (long-term outcomes)	Incomplete outcome data (short-term outcomes)	Incomplete outcome data (long-term outcomes)	Selective outcome reporting	Other sources of bias
Ahrens, 2003 ¹	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes
Campbell, 2003 ²	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Clayton, 2007 ³	Yes	No	No	Yes	No	Yes	Yes	Yes	Yes	Yes
Cowan, 2003 ⁴	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Gade, 2008 ⁵	Yes	Yes	No	No	No	No	Yes	Yes	Yes	Yes
Hanks, 2002 ⁶	No	No	Yes	Yes	No	No	Yes	Yes	Yes	Yes
Jacobsen, 2011 ⁷	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Kaufer, 2008 ⁸	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Lautrette, 2007 ⁹	Yes	Yes	No	Yes	No	Yes	Yes	Yes	Yes	Yes
Lilly, 2000 ¹⁰	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Lilly, 2003 ¹¹	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Molloy, 2000 ¹²	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Mosenthal, 2008 ¹³	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Muir, 2010 ¹⁴	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Norton, 2007 ¹⁵	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Penticuff, 2005 ¹⁶	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Sampson, 2011 ¹⁷	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Schneiderman, 2000 ¹⁸	No	No	No	No	No	No	Yes	Yes	Yes	Yes
Schneiderman, 2003 ¹⁹	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Tulsky, 2011 ²⁰	Yes	Yes	No	No	No	No	Yes	Yes	Yes	Yes

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Evidence Table 17. Outcomes reported in studies addressing communication

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Ahrens et al, 2003 ¹	LOS	Hospital LOS	151 patients (108 in standard practice, 43 in intervention)	39-40% African American, 58-60% white, 1-2% Asian	Control 16.4 days, intervention 11.3 days; p = 0.03		None	None
	LOS	ICU LOS			Control 9.5 days, intervention 6.1 days; p=0.009			
	Mortality	Hospital Mortality				Control 93%, Intervention 74%; p =0.14		
	Cost				Hospital variable direct charge per case: control \$24,080, intervention \$15,559; p=0.01; Hospital Varian indirect charge per case: control \$8035, intervention \$5087; p=0.07; Fixed chargecase: Control \$8485, Intervention \$5320; p=0.006;			
Cowan, 2003 ²	Decision to forgo Resuscitation		873	6% African Americans	Receiving the intervention increased the average predicted probability of deciding to forgo resuscitation by about 50%, from 18% to 28%. (OR 1.81, p=0.017)		None	
	Decision to give comfort care only				Receiving the intervention increased the average predicted probability of choosing comfort care by 59%, from 14% to 22%. (OR 1.94, p= 0.018)		None	

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Cowan, 2003 ² (continued)	Decision to treat aggressively				Receiving the intervention increased the average predicted probability of choosing aggressive care by almost 90%, from 10% to nearly 20%. (OR 2.30, p=0.002).		None	
	Satisfaction; Overall satisfaction with care					Intervention vs. Control (OR 0.68, p=0.14)	None	
	Satisfaction with information provided					Intervention vs. Control (OR 0.86, p=0.44)	None	
	Satisfaction; Satisfaction with involvement in decision making					Intervention vs. Control (OR 0.84, p=0.54)	None	
Campbell & Guzman, 2003 ³	LOS	Hospital los (days in means)	Total 81; retrospective control 40, intervention 41	None noted.	Global cerebral ischemia patients: control 8.6 days, intervention 4.7 days; p < 0.001	Multi-system organ failure patients: control 20.6 days, intervention 15.1 days; p = 0.063	None	None
	LOS	ICU LOS (days in means)			GCI: control 7.1 days, Intervention 3.7 days; p < 0.01	MOSF: control 10.7 days, intervention 10.4 days; p = 0.735		
	LOS	DNR status (days in means)			MOSF to DNR: control 4.7 days, intervention 1.5 days; p < 0.05;	MOSF admission to DNR: control 10.7 days, intervention 10.4 days; p = 0.735; GCI admission to DNR: control 3.5 days, intervention 2.8 days; p = 0.063		

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Campbell & Guzman, 2003 ³ (continued)	LOS	CMO status (days in means)			MOSF to CMO: control 7.3 days, intervention 2.2 days, $p < 0.05$; GCI hosp admission to CMO: control 6.3 days, intervention 3.5 days; $p < 0.05$			
	LOS	MOSF to death (days in means)			Control 5.8 days, intervention 2.1 days; $p < 0.05$			
	Use of hospital resources	Therapeutic Intervention Scoring System - after withhold support				MOSF: Decrease of: Control 1.8, intervention 4.1; $p=0.37$, GCI: Decrease of: Control 3.8, intervention 4.3; $p=0.41$		
		Therapeutic Intervention Scoring System - after make patient CMO			MOSF: Decrease of: control 12, intervention 25.6; $p < 0.05$	GCI: Decrease of: control 19.4, intervention 15.4; $p=0.34$		

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Clayton, 2007 ⁴	Primary outcome: total number of patient questions during the consultation and patient preference for information	Spiel-Berger State Anxiety Inventory	174 patients	None	Patients in the QPL group asked 2.31 times (95% CI, 1.68 to 3.18 times) more questions directly requesting for information during the consultation than controls (P .0001). 23% (95% CI, 11% to 37%) more items were discussed during consultations with QPL patients than controls (P .0001).			Thespis a 16-page A5 booklet (Appendix, online only) containing 112 questions grouped into nine topics encompassing issues that may be discussed with a physician or another health professional. Unmet patient information need, was reduced by the QPL.
	Satisfaction, Patient satisfaction with the consultation					Patients were highly satisfied with the consultation in both groups (mean score out of 125: QPL, 110.1 v control, 110.3; 95% CI for difference, 3.4 to 2.9)		
	Other Patient anxiety					Patient anxiety scores were similar in both groups (mean, 40.3 in both groups; 95% CI for difference, 2.7 to 2.7).		

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Muir, 2010 ^b	LOS		480	None		Control 22.84 (13.36) vs. Intervention 24.86 (13.04), P=0.07	None	
	LOS; ICU stay					Control 13.44 (9.18) vs. Intervention 14.41 (9.85), P=0.16	None	
	Presence of Living will					Control 30 (22.2) vs. Intervention 53 (15.3), P=0.07	None	
	DNAR order					Control 46 (34.1) vs. Intervention 107 (30.9), P=0.51	None	
	Number of Tracheotomy					Control 74 (55.6) vs. Intervention 169 (49.3), P=0.21	None	
	ICU Mortality					Control 26 (19.3) vs. Intervention 67 (19.4), P=0.98	None	
	Post-discharge Mortality					Control 19 (21.6) vs. Intervention 38 (15.9), P=0.03	None	

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Gade, 2008 ⁶	Patient symptoms; Primary study outcomes: symptom control	Physical Area scale of the Modified City of Hope Patient Questionnaires, Emotional Relationship Area and Spiritual Area scales, Place of Care Environment scale and the Doctors, Nurses Other Care Providers Communication scale, Eastern Cooperative Oncology Group performance scale.	517 patients	None		No difference between IPCS and UC groups for patient symptom control.	None	This study provides evidence for the positive impact of IPCS consultations on satisfaction with care and decreased health care costs. It also contributes new information on the impact of this service on ICU admissions and hospice utilization.
	Satisfaction; Primary study outcomes: patient satisfaction				IPCS group reported higher mean satisfaction for both the Place of Care Environment scale (IPCS: 6.8; UC: 6.4, p .001.)			
	QOL; Primary study outcomes					No difference between IPCS and UC groups for quality of life.		

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Gade, 2008 ^b (continued)	Psychosocial symptoms and support; levels of emotional Primary study outcomes: spiritual support					No difference between IPCS and UC groups for emotional and spiritual support.		
	Primary study outcomes: total health services costs at 6 months post index hospitalization				Total mean health costs for the IPCS group were lower by \$6,766 per patient compared to UC patients (IPCS: \$14,486; UC: \$21, 252, p 0.001).			
	Secondary measures: survival					No difference between IPCS and UC groups for survival.		
	Secondary measures: number of advance directives (ads) at discharge				IPCS patients completed significantly more ADS at hospital discharge than UC patients (91.1% vs. 77.8%; p0.001),			
	Secondary measures: hospice utilization within the 6 months post index hospitalization.				IPCS patients had significantly longer median hospice stays than UC participants (IPCS: 24 days; UC: 12days, p0.04)			
	Secondary measures: ICU admissions				Fewer ICU admissions IPCS 12 vs. UC 21 (P=0.04)			

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Hanks, 2002 ⁷	Symptom	VAS, mood (Memorial Pain Assessment Card), emotional (WONCA scale)	261	None		No diff; Symptom severity (p=0.48), Mood (p=0.45), emotional problems (0.58)		
	Satisfaction	Macadam's Assessment of Suffering Questionnaire, FAMCARE scale, the Hospital Anxiety and Depression scale	261	None		No p values given but no apparent differences.		This study didn't show a significant difference between the 'full-PCT' and 'telephone-PCT' in respect of the primary outcome measures, and particularly symptoms and HRQOL
	QOL, Health-related quality of life	EORTC QLQ-C30 questionnaire,				No significant diff between groups (p = 0.45).		
	LOS					Full PCT 14.7 (9.4) days vs. Telephone PCT 13.2 (9.6) days. P value not given		
Jacobsen, 2011 ⁸	Advance care plan discussion		899	None	33.8% intervention vs. 21.2% control, p<0.001	None	None	
	Presence of an order at the time of discharge to limit life-sustaining treatment				19.1% intervention vs. 13.9% control, p<0.044	None	None	

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Kaufer, 2008 ⁹	Overall satisfaction with hospital experience; Satisfaction	Family Satisfaction with Care Questionnaire	88	67% African American		No significant change	None	
	Satisfaction with amount of treatment received	Family Satisfaction with Care Questionnaire			Increased from 44% to 75%(P = .03)		None	
	Satisfaction; Patient life not prolonged or shortened unnecessarily	Family Satisfaction with Care Questionnaire			Increased from 47% pre-intervention to 73% post-intervention (P =0.016)		None	
	Satisfaction Satisfaction with understanding of information	Family Satisfaction with Care Questionnaire			Increased from 44% to 73% (P=0.005) post-intervention		None	
	Distress Emotional support	Family Satisfaction with Care Questionnaire			Increased from 76% to 86% (P<0.05)		None	
	Patient Symptom management symptoms	Family Satisfaction with Care Questionnaire				No significant change	None	
	Other Involvement in decision making	Family Satisfaction with Care Questionnaire			Increased from 40% to 70% (P = .004).		None	

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Kaufer, 2008 (continued)	Satisfaction with frequency of communication Other	Family Satisfaction with Care Questionnaire			Communication from doctors (44% to 76%, $p=0.003$), from nurses (72% to 91%, $p=0.021$) of information, honesty of information, and completeness of information increased from 44% to 73%, 56% to 80%, and 49% to 78%, respectively ($P=0.005$, 0.015, and 0.005 respectively).		None	
Lautrette et al, 2007 ¹⁰	Distress; Caregiver distress	Impact of Event Scale Score	Control group 63 patients, Intervention group 63 patients.	86 (intervention) or 88% (control) of patients were of French descent	Intervention IES score median 27 (IQR 18-42) vs. Control IES score 39 (IQR 25-48); $p=0.02$; 45% of families in intervention group at risk for PTSD and 69% of families in control group at risk for PTSD		None noted.	Symptoms of anxiety & depression - also significantly different; most measures of effectiveness of overall information provided were not statistically significantly different; use of non-beneficial interventions (ventilation, others) not significantly different

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Lautrette et al, 2007 ¹⁰	Psychosocial symptoms and Caregiver distress support	Hospital Anxiety and Depression Scale			Intervention HADS score median 11 (IQR 8-18) vs. Control HADS 17 (IQR 11-25); p=0.004;			
	LOS	Number of days in ICU from admission to decision to forgo life-sustaining treatments				Intervention 2 days (IQR 2-14), Control 5 days (IQR 2-10), p=0.38		
	Discussion of goals of care by physicians on rounds				Discussion of goals of care by physicians on rounds increased from 4% to 36% of patient-days.			
	Do not resuscitate and Withdrawal of life support					DNR (43%) and WD (24%) were unchanged.		
	Mortality rate					During intervention, rates of mortality (14%),		

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Lilly, 2003 ¹¹	Length of stay (primary vs. Secondary not stated)	ICU LOS	2495 Patients	None	Length of stay in the ICU was reduced from 4 [2–11] to 3days [2–6 days, interquartile range; n 2361]	None	None	Intensive communication is a process based intervention that encourages the use of advanced supportive technology when it is effective for accomplishing patient-directed goals and facilitates acceptance of a comfort-focused care plan for dying patients.
	Mortality	Mortality			ICU mortality rate in follow-up study was 18.0% and lower than the rate of 31.3% observed for our pre-intervention group (chi-square p .001)			
	LOS	Adjustment for acute physiology and chronic health evaluation 3 score	530	African Americans, Hispanics, Asians	4 days (2 to 11days) to 3 days (2 to 6 days) P= 0.01. APACHE 3 score [risk ratio- 0.81, 95% confidence interval (CI), 0.66 to 0.99, P- 0.04	None	None	

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Lilly, 2000 ¹²	Mortality				7 of 35 patients (20%) died in the pre-intervention period, and 5 of 102 patients (5%) died in the intensive communication period (P = 0.02).	None	None	
	Rate of family non-consensus				171 days per 1,000 patient-days to 16 days per 1,000 patient-days (1.7 to 0.09 days per patient) after the intervention (P=0.001)	None	None	
	Rate of provider non-consensus				65 days per 1,000 patient-days to 4 days per 1,000 patient-days, (0.56 to 0.02 days per patient)	None	None	
Molloy, 2000 ¹³	Satisfaction	Satisfaction questionnaires	1133	None		Mean diff -0.16 [-0.41-0.1], P=0.24	None	
	Hospital cost					Hosp cost: intervention Can\$1772, control Can\$3869, (p=0.003); total health care & implement cost intervention Can\$3490, control Can\$5239 (p=0.01)		
	Risk of hospitalization and # hosp days				Risk of hosp: Intervention 0.27, control 0.48 (p=0.001); # hosp days: intervention 2.61, control 5.86 (p=0.01)		None	
	Mortality rate					Intervention and control homes (24% vs. 28%; P = .20).	None	

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Mosenthal, 2008 ¹⁴	LOS; Hospital LOS	Glasgow Coma Scale, severe head injury, Injury Severity Score.	367	None	In baseline patients ICU LOS mean 7.6, median 3, hospital LOS mean 14.4, median 3.5, In intervention patients ICU LOS mean 6.1, median 1, hospital LOS mean 6.5, median 1.5		None	
Norton, 2007{ #16225}	LOS; MICU LOS		191	African American (19.4%), Hispanic (3%)	The proactive PC intervention group was 8.96 days compared with 16.28 days for the usual care group, a statistically significant difference of 7.32 days (p=0.0001)		None	
	LOS					The usual care group: 41.40 days compared with 35.8 days for the proactive PC intervention group (p=0.5011)	None	
	Mortality rate					In hospital mortality - 55.4% control vs. 59.5% intervention - no change the MICU death rate was 25 of 65 (38.5%) in the usual care group and 46 of 126 (36.5%) in the proactive PC intervention group. (p=0.6128).	None	

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Penticuff, 2005 ¹⁹	Parental satisfaction with participation, care and relationship ;Satisfaction	Collaboration and Satisfaction About Care Questionnaire	154	African American (15%), Hispanic (34%)		Intervention vs. Control with care 64.98 vs. 65.69 (p<0.610), with relationship 193.11 vs. 193.35 (p <0.960)	None	
	Parent's comprehension of medical information	Subscale of Parents' Understanding of Infant Care and Outcomes Questionnaire			Had fewer unrealistic concerns 4.32 vs. 8.56 (p=0.018)		None	
	Parent's understanding of infant care	Five-point Likert scale of 30 items.			Less uncertainty about infant care intervention vs. Control mean 1.92 vs. 3.82 (p=0.003)		None	
	Decision conflicts	Decision Conflict Scale			Intervention vs. Control; mean 45.88 vs. 59.10 (p<0.001)		None	
	Amount of shared decision making				Intervention vs. Control 139 vs. 122.69 (p=0.010)		None	

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Sampson, 2011 ¹⁶	Number of carers making Advanced care planning		32			Only seven carers made ACPs. The care planning discussion was well received, but few carers wrote an ACP, despite intensive support from an experienced nurse specialist.	none	Attrition precluded statistical comparison of control and intervention groups, but some trends are suggested by the data.
	Carer satisfaction	Life satisfaction scale LSQ				Intervention vs Control at baseline: 4.5(1.1) vs 4.6(1.2), at 6months 5.4(0.9) vs 5.5(0.6)		
	carer distress	Kessler distress scale KD10			Intervention vs Control at baseline; 20.7(6.8) vs 22.7(10.3), at 6months 14.6(3.4) vs 15.0(4.4). Improvement in the months following the patient's index admission			
	Patient pain	visual analogue scale VAS				no observable trends in the carer ratings of patients' pain.		
	Patient distress	visual analogue scale VAS				no observable trends in the carer ratings of patients' distress.		

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Schneiderman, 2003 ¹⁷	LOS; Hospital days		546	African Americans, Hispanics, Asians	Intervention (n=173) vs. Control patients (n=156) hospital days (-2.95 days, P=.01)		None	This study showed that ethics consultations in the ICU were helpful in addressing treatment conflicts.
	Days receiving ventilation				Intervention vs. Control patients (-1.7 days, P=.03)		None	
	Days receiving artificial nutrition hydration					Days receiving nutritionhydration (-1.03days, P=.14)	None	
	Days receiving artificial nutrition and hydration				Control 12.0 vs. Intervention 4.1 (p 0.05)		None	
	Days receiving ventilation				Control 11.4 vs. Intervention 3.7 (p 0.05)		None	
	% of patients receiving CPR, DNAR, gastrostomy, tracheotomy, transfusion, ventilator					No difference.		
	Overall mortality					There were no differences - p=1.0 - in overall mortality between the control patients and patients receiving ethics consultations.	None	
Schneiderman, 2000 ¹⁸	LOS; ICU days		70	African Americans, Hispanics, Asians	There was a reduction in ICU days: control13.2 days vs. Intervention 4.2 days (p 0.03)		None	

Evidence Table 17. Outcomes reported in studies addressing communication (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Tulsky, 2011 ¹⁹	Audio recordings to measure the emotion-handling skills outcomes of providers		264	10% Black, 4% Hispanic	The mean number of empathic statements per conversation increased (mean, 0.8 [SD, 1.3] in the intervention group vs. 0.4 [SD, 0.8] in the control group). This value increased more among oncologists in the intervention group (adjusted rate ratio, 1.9 [CI, 1.1 to 3.3]; P 0.024)			
	Patient perceptions; trust, perceived empathy, therapeutic alliance, perceived knowledge of patient, perceived belief that provider cares, perceived belief that provider understood patient as a whole person				Trust scale: intervention versus control; 4.7 (4.6-4.8) vs 4.6 (4.5-4.7), mean difference 0.1 90.0-0.2), p value= 0.036.	Perceived empathy scale p value= 0.058, Therapeutic alliance scale pvalue= 0.27, perceived knowledge of patient p value= 0.28, perceived belief that provider cares p value= 0.63, perceived belief that oncologist understood patient as a whole pvalue= 0.093	none	In this study, the control oncologists performed slightly worse in the postintervention phase. To improve the quality of communication in medical encounters, more physicians should receive communication skills training that includes individualized, reflective feedback.

Abbreviations: Can \$=Canadian dollar; CMO=Comfort measures only; CPR=Cardiopulmonary resuscitation; DNARDNR=Do not attempt resuscitation; EORTC QLQ C-30=European organization for research and treatment of cancer quality of life questionnaire; GCI=Global cerebral ischemia; HADS=Hospital anxiety and depression scale; HRQOL=Health related quality of life; ICU=Intensive care unit; IPCS=Interdisciplinary palliative care service; IES=Impact of event scale; IQR=Interquartile range; LOS=Length of stay; MICU=Medical intensive care unit; MOSF=Multi-organ systems failure; PC=Palliative care; PCT=Palliative care team; PTSD=Post-traumatic stress disorder; QOL=Quality of life; QPL=Question prompts lists; UC=Usual care; WD=Withdrawal of life support; VAS=Visual analog scale; WONCA=World Organization of National Colleges and Academic

Evidence Table 17 Reference List

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- improve end-of-life care in a medical ICU. *Chest* 2003; 123(1):266-71.
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Evidence Table 18. Description of interventions for studies addressing quality improvement

Author, year	Integrative vs. consultative	Target of intervention
Campion, 2011 ¹	Consultative: interacts with providers	Symptom Assessment and Use of Hospice
Detmar, 2002 ²	Other neither	Assessments
Meyers, 2011 ³	Consultative: Interacts with patients and families	Quality of Life, Problem Solving
Mills, 2009 ⁴	Other neither	Assessments
Rosenbloom, 2007 ⁵	Consultative: Interacts with both	Assessments
Taenzer, 2000 ⁶	Other neither	Quality of life assessment
Velikova, 2004 ⁷ , Velikova 2010 ⁸	Integrative	Case management

Evidence Table 18 Reference List

1. Campion FX, Larson LR, Kadlubek PJ, Earle CC, Neuss MN. Advancing performance measurement in oncology. *Am J Manag Care* 2011; 17 Suppl 5 Developing:SP32-6.
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Evidence Table 19. Description of quality improvement elements in studies addressing quality improvement

Author, year	Facilitated relay of clinical data to providers?	Provider education?	Patient family caregiver education?	Organizational change?
Campion, 2011 ¹	No	No	No	No
Detmar, 2002 ²	Yes	Yes	Yes	No
Meyers, 2011 ³	No	No	Yes	No
Mills, 2009 ⁴	Yes	Yes	No	No
Rosenbloom, 2007 ⁵	Yes	No	No	No
Taenzer, 2000 ⁶	Yes	Yes	No	No
Velikova, 2004 ⁷ , Velikova 2010 ⁸	Yes	Yes	No	Yes

Evidence Table 19 Reference List

1. Campion FX, Larson LR, Kadlubek PJ, Earle CC, Neuss MN. Advancing performance measurement in oncology. *Am J Manag Care* 2011; 17 Suppl 5 Developing:SP32-6.
2. Detmar SB, Muller MJ, Schornagel JH, Wever LD, Aaronson NK. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *JAMA* 2002; 288(23):3027-34.
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Evidence Table 20. Risk of bias assessment of studies addressing quality improvement

Author, year	Sequence generation	Allocation concealment	Binding of personnel (short-term outcomes)	Blinding of outcome assessors (short-term outcomes)	Binding of personnel (long-term outcomes)	Blinding of outcome assessors (long-term outcomes)	Incomplete outcome data (short-term outcomes)	Incomplete outcome data (long-term outcomes)	Selective outcome reporting	Other sources of bias
Campion, 2011¹	No	No	No	No	No	No	Yes	Yes	Yes	No
Detmar, 2002 ²	Unclear	No	No	Unclear	No	Unclear	Yes	Yes	Yes	No
Meyers, 2011 ³	Yes	Unclear	No	Unclear	Unclear	Unclear	Yes	Yes	Yes	No
Mills, 2009 ⁴	Yes	Unclear	No	No	No	No	Yes	Yes	Yes	Yes
Rosenbloom, 2007 ⁵	Unclear	Unclear	No	No	No	No	Yes	Yes	Yes	Yes
Taenzer, 2000 ⁶	No	No	No	No	No	No	No	Yes	Yes	No
Velikova, 2004 ⁷ , Velikova, 2010 ⁸	Unclear	Unclear	Unclear	Unclear	Unclear	Unclear	No	No	No	Unclear

Evidence Table 20 Reference List

1. Campion FX, Larson LR, Kadlubek PJ, Earle CC, Neuss MN. Advancing performance measurement in oncology. *Am J Manag Care* 2011; 17 Suppl 5 Developing:SP32-6.
2. Detmar SB, Muller MJ, Schornagel JH, Wever LD, Aaronson NK. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *JAMA* 2002; 288(23):3027-34.
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Evidence Table 21. Outcomes reported in studies addressing quality improvement

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Campion, 2011 ¹	Quality of Care	Pain assessed appropriately before death	644 sites	NR	Sites reporting in multiple periods vs. sites reporting only in Fall 2010 (65.84% vs. 46.89%, p<0.001)			
		Dyspnea addressed appropriate before death	644 sites		Sites reporting in multiple periods vs. sites reporting only in Fall 2010 (71.37% vs. 60.82%, p=0.005)			
		Hospice or palliative care discussed	641 sites			Sites reporting in multiple periods vs. sites reporting only in Fall 2010 (21.54% vs. 17.00%, p=0.152)		
		Hospice/palliative care addressed appropriately	633 sites		Sites reporting in multiple periods vs. sites reporting only in Fall 2010 (65.60% vs. 54.65%, p=0.005)			
		Hospice or palliative care used	644 sites		Sites reporting in multiple periods vs. sites reporting only in Fall 2010 (52.92% vs. 50.01%, p=0.046)			
		Hospice enrollment more than 3 days before death	628 sites		Sites reporting in multiple periods vs. sites reporting only in Fall 2010 (40.95% vs. 31.45%, p=0.015)			

Evidence Table 21. Outcomes reported in studies addressing quality improvement (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Detmar, 2002 ²	Other	Composite communication score calculated by summing all HRQL-related topics that were discussed	214	Not reported	Composite score 4.7 (SD 2.3) intervention group, 3.7(1.9) control group (p=0.01)	Physical functioning	None	Physician-level randomization
	Satisfaction	Patient Satisfaction Questionnaire C				Not significantly improved		
	QOL Physician awareness of patient's QOL, QOL-related medications and counseling referrals	SF-36				Not significantly improved		

Evidence Table 21. Outcomes reported in studies addressing quality improvement (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Meyers, 2011 ³	Quality of Life	City of Hope Quality of Life Instruments for Patients of Caregivers	476	AA: 43	Caregiver QOL scores in the intervention arm declined at less than half the rate of the control arm (p=0.02)	No difference for patients		Effect size: 0.3 standard deviation
	Problem Solving	Social Problem Solving Inventory-Revised		AsianPI: 61		Neither patients (p=0.86) nor caregivers (p=0.21) showed any change in problem solving skills		
	Quality of Life: Psychological	City of Hope Quality of Life Instruments for Patients of Caregivers		White: 719		There was no change in psychological well-being among patients (p=0.82)		
	Quality of Life: Social	City of Hope Quality of Life Instruments for Patients of Caregivers		Native American: 8		SCEI caregivers scored higher in the social subdomain (p=0.09)		
	Quality of Life: Physical	City of Hope Quality of Life Instruments for Patients of Caregivers		Hispanic: 72		There was no change in physical well-being among patients (p=0.97) and caregivers (p=0.61)		
	Quality of Life: Spiritual	City of Hope Quality of Life Instruments for Patients of Caregivers			Spiritual well-being among caregivers improved in the SCEI group relative to control (p<0.001)			

Evidence Table 21. Outcomes reported in studies addressing quality improvement (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Mills, 2009 ⁴	QOL Diary utilization, communication, satisfaction, discussion of problems		115	None	Palliative Care QOL Index (communication, discussion)	QOL(primary outcome), 45 QOL measurements, satisfaction,	Clinical deterioration	Most patients gave no feedback to providers- no chance for intervention
Rosenbloom, 2007 ⁵	Clinical treatment changes							
Taenzer, 2000 ⁶	QOL	EORTC QLQ - c30	53	None discussed		Significantly different in 3 of 15 function and symptom scales - experimental group better only for dyspnea	None noted	"Clinic staff behavior may have changed since they were aware of the purpose of the study, even before the introduction of the QOL screening reports."; pre-post study, small sample size
	Satisfaction	PDIS-pt satisfaction questionnaire				Not significantly improved		
	Other EORTC items addressed during the visit significantly higher for experimental group; no significant difference in medical record audit for number of EORTC categories charted							

Evidence Table 21. Outcomes reported in studies addressing quality improvement (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
Velikova, 2004 ⁷ ; Velikova, 2010 ⁸	Quality of care measures		286	Not reported	Symptom communication: 3.3(SD 1.63) vs. 2.7 (1.53) (p=0.03) (# of symptoms in the questionnaire mentioned during encounter)	Communication about other symptoms, issues not significantly improved		In general, significant differences with control group but not with the group that had HRQOL measured but no feedback to physicians; attrition rate of 30%; randomized at patient level
	Quality of life	Functional assessment of cancer therapy-general questionnaire score			Estimate effect: 8.01 (SE 2.84), p=0.006 (intervention vs. Control)			

Evidence Table 21. Outcomes reported in studies addressing quality improvement (continued)

Author, year	Outcome measures	Measures	Sample size	Disparities	Outcomes: Benefits. Significantly improved	Outcomes: Benefits. Not significantly improved	Outcomes: Harms	Other key information
	Satisfaction	Likert scale (2 questions)				Not significantly improved		
	Other: patient perceptions of communication, continuity and coordination	Medical care Questionnaire			Significantly Different for 23 subscales - estimate effect - ; communication, 4.51 (p=0.03); preferences 3.32, p=0.027 (intervention vs. Control)	Coordination not significantly improved		

Abbreviations: EORTC-QLQ=European organization for research and treatment of cancer quality of life questionnaire; HRQOL=Health related quality of life; PDIS=Patient-doctor interaction scale; QOL=Quality of life; SF-36=Short form health survey with 36 questions

Evidence Table 21 Reference List

1. Campion FX, Larson LR, Kadlubek PJ, Earle CC, Neuss MN. Advancing performance measurement in oncology. *Am J Manag Care* 2011; 17 Suppl 5 Developing:SP32-6.
2. Detmar SB, Muller MJ, Schornagel JH, Wever LD, Aaronson NK. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *JAMA* 2002; 288(23):3027-34.
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Appendix F. Evidence Grading: Hospice and Nursing Homes

Table 1. Evidence grading for hospice and nursing home settings

Number of studies; subjects	Domains pertaining to strength of evidence				Magnitude of effect and strength of evidence
	Risk of bias:	Consistency	Directness for outcome	Precision; Study heterogeneity	Absolute risk difference per 100 patients
Patient symptoms					Low SOE
4;1675	RCTmedium	Inconsistent	Direct	Not applicable; medium	Improvement with intervention; low
1; 176	Non-RCTmedium	Inconsistent	Direct	Not applicable; medium	Improvement with intervention; low
Utilization					Low SOE
2;1338	RCTmedium	Consistent	Indirect	Not applicable; medium	Improvement with intervention; low
2;895	Non-RCTmedium	Consistent	Indirect	Not applicable; medium	Improvement with intervention; low