Comparative Effectiveness Review
Number 237

Integrating Palliative Care in Ambulatory Care of Noncancer Serious Chronic Illness

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-based Practice Centers (EPCs), sponsors the development of systematic reviews to assist public- and private-sector organizations in their efforts to improve the quality of healthcare in the United States. These reviews provide comprehensive, science-based information on common, costly medical conditions, and new healthcare technologies and strategies.

Systematic reviews are the building blocks underlying evidence-based practice; they focus attention on the strength and limits of evidence from research studies about the effectiveness and safety of a clinical intervention. In the context of developing recommendations for practice, systematic reviews can help clarify whether assertions about the value of the intervention are based on strong evidence from clinical studies. For more information about AHRQ EPC systematic reviews, see www.effectivehealthcare.ahrq.gov/about/epc/evidence-synthesis.

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If you have comments on this systematic review, they may be sent by mail to the Task Order Officer named below at: Agency for Healthcare Research and Quality, 5600 Fishers Lane, Rockville, MD 20857, or by email to epc@ahrq.hhs.gov.

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Key Informants

In designing the study questions, the EPC consulted several Key Informants who represent the end-users of research. The EPC sought the Key Informant input on the priority areas for research and synthesis. Key Informants are not involved in the analysis of the evidence or the writing of the report. Therefore, in the end, study questions, design, methodological approaches, and/or conclusions do not necessarily represent the views of individual Key Informants.

Key Informants must disclose any financial conflicts of interest greater than $5,000 and any other relevant business or professional conflicts of interest. Because of their role as end-users, individuals with potential conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any conflicts of interest.

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In designing the study questions and methodology at the outset of this report, the EPC consulted several technical and content experts. Broad expertise and perspectives were sought. Divergent and conflicted opinions are common and perceived as healthy scientific discourse that results in a thoughtful, relevant systematic review. Therefore, in the end, study questions, design, methodologic approaches, and/or conclusions do not necessarily represent the views of individual technical and content experts.

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Peer Reviewers must disclose any financial conflicts of interest greater than $5,000 and any other relevant business or professional conflicts of interest. Because of their unique clinical or content expertise, individuals with potential nonfinancial conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential nonfinancial conflicts of interest identified.

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Integrating Palliative Care in Ambulatory Care of Noncancer Serious Chronic Illness

Structured Abstract

Objectives. To evaluate availability, effectiveness, and implementation of interventions for integrating palliative care into ambulatory care for U.S.-based adults with serious life-threatening chronic illness or conditions other than cancer and their caregivers We evaluated interventions addressing identification of patients, patient and caregiver education, shared decision-making tools, clinician education, and models of care.

Data sources. We searched key U.S. national websites (March 2020) and PubMed®, CINAHL®, and the Cochrane Central Register of Controlled Trials (through May 2020). We also engaged Key Informants.

Review methods. We completed a mixed-methods review; we sought, synthesized, and integrated Web resources; quantitative, qualitative and mixed-methods studies; and input from patient/caregiver and clinician/stakeholder Key Informants. Two reviewers screened websites and search results, abstracted data, assessed risk of bias or study quality, and graded strength of evidence (SOE) for key outcomes: health-related quality of life, patient overall symptom burden, patient depressive symptom scores, patient and caregiver satisfaction, and advance directive documentation. We performed meta-analyses when appropriate.

Results. We included 46 Web resources, 20 quantitative effectiveness studies, and 16 qualitative implementation studies across primary care and specialty populations. Various prediction models, tools, and triggers to identify patients are available, but none were evaluated for effectiveness or implementation. Numerous patient and caregiver education tools are available, but none were evaluated for effectiveness or implementation. All of the shared decision-making tools addressed advance care planning; these tools may increase patient satisfaction and advance directive documentation compared with usual care (SOE: low). Patients and caregivers prefer advance care planning discussions grounded in patient and caregiver experiences with individualized timing. Although numerous education and training resources for nonpalliative care clinicians are available, we were unable to draw conclusions about implementation, and none have been evaluated for effectiveness. The models evaluated for integrating palliative care were not more effective than usual care for improving health-related quality of life or patient depressive symptom scores (SOE: moderate) and may have little to no effect on increasing patient satisfaction or decreasing overall symptom burden (SOE: low), but models for integrating palliative care were effective for increasing advance directive documentation (SOE: moderate). Multimodal interventions may have little to no effect on increasing advance directive documentation (SOE: low) and other graded outcomes were not assessed. For utilization, models for integrating palliative care were not found to be more effective than usual care for decreasing hospitalizations; we were unable to draw conclusions about most other aspects of utilization or cost and resource use. We were unable to draw conclusions about caregiver satisfaction or specific characteristics of models for integrating palliative care. Patient preferences for

appropriate timing of palliative care varied; costs, additional visits, and travel were seen as barriers to implementation.

Conclusions. For integrating palliative care into ambulatory care for serious illness and conditions other than cancer, advance care planning shared decision-making tools and palliative care models were the most widely evaluated interventions and may be effective for improving only a few outcomes. More research is needed, particularly on identification of patients for these interventions; education for patients, caregivers, and clinicians; shared decision-making tools beyond advance care planning and advance directive completion; and specific components, characteristics, and implementation factors in models for integrating palliative care into ambulatory care.

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Evidence Summary

Main Points

For integrating palliative care into ambulatory care for adults with serious life-threatening chronic illness and conditions other than cancer in U.S. settings:

- A variety of resources exist, particularly for patient and caregiver education and clinician education and training, but few have been evaluated for effectiveness or implementation.
- Shared decision-making tools may increase patient satisfaction and advance directive documentation.
- The models evaluated for integrating palliative care may have little to no effect on reducing overall symptom burden and were not more effective than usual care for improving health-related quality of life or depressive symptom scores but were more effective for increasing advance directive documentation.
- Patients and caregivers prefer advance care planning discussions grounded in patient and caregiver experiences and individualized for timing.

Background and Purpose

In the United States, most care for adults with serious life-threatening chronic illness or conditions (e.g., advanced heart failure, chronic obstructive pulmonary disease, or end-stage renal disease) occurs in ambulatory settings. Care for these patients can be complex, as the patients often experience high symptom burden and decreased health-related quality of life. Patients may benefit from the integration of palliative care into ambulatory care that is made possible either through the incorporation of palliative care services or by training ambulatory care clinicians in palliative care.

The key decisional dilemma for clinicians, patients, and caregivers is "How can people with serious life-threatening chronic illness or conditions best receive ambulatory care that integrates appropriate palliative care approaches or educational services, materials, or shared decision-making tools?" An existing recent systematic review addresses integrating palliative care into ambulatory oncology, so this review focuses on other serious chronic illness and conditions.

Methods

We completed a mixed-methods review focusing on serious chronic illnesses other than cancer; we synthesized and integrated evidence from key U.S. national websites (March 2020), quantitative effectiveness and qualitative implementation studies, and input from patient/caregiver and clinician/stakeholder Key Informants. We completed searches for studies in May 2020. With input from the stakeholders and experts, we considered effectiveness as those outcomes that are within the domains of palliative care and have evidence for associations with positive patient and caregiver outcomes. We performed meta-analyses when appropriate.

Results

For each of the Key Questions below, we addressed three parts:

- What is available?
- What is the effectiveness?

- How is it implemented?

We then integrated these parts for each Key Question.
We included 46 Web resources, 20 quantitative effectiveness studies and 16 qualitative implementation studies. We identified no mixed-methods studies.

Key Question 1. How can we identify those patients who could benefit from palliative care in ambulatory care settings, and what is the evidence for effectiveness and implementation of these methods?

- A variety of potential prediction models, tools, and triggers are available, mainly for general populations rather than specific illnesses or conditions, but none were evaluated for effectiveness or implementation.
- Multimodal intervention studies have included triggers together with shared decision-making tools for primary care and advanced heart failure.
- Clinician/stakeholder Key Informants perceived that methods for patient identification and selection, such as triggering/reminder systems, are helpful, and that time and space to introduce palliative care in the ambulatory care setting is critical.
- Patient/caregiver Key Informants felt that palliative care options should be provided early and offered to all patients with serious illnesses.

Key Question 2. What educational resources are available for patients and caregivers in ambulatory care about integrating palliative care, and what is the evidence for their effectiveness and implementation?

- Although a variety of relevant patient and caregiver education tools are available, mainly for general populations rather than specific illnesses or conditions, none were evaluated for effectiveness or implementation.
- Only one of the nine models for integrating palliative care that were evaluated for effectiveness included patient/caregiver education as a component.
- Patient/caregiver Key Informants felt that education was very important, that clinicians should initiate discussions face-to-face and that clarifying the definition of palliative care is key. They also felt that these discussions should be done in a patient-friendly, easily understandable manner and format, aided by educational materials.

Key Question 3. What palliative care shared decision-making tools for serious life-threatening chronic illness or conditions are available for clinicians, patients, and caregivers in ambulatory care, and what is the evidence for their effectiveness and implementation?

- All identified shared decision-making tools addressed advance care planning only.
- Shared decision-making tools may improve patient satisfaction with communication and increase advance directive documentation compared with usual care (SOE: Low for both).
- We were unable to draw conclusions about the effectiveness of shared decision-making tools for patient symptoms of depression or caregiver satisfaction.
- Qualitative evidence supported grounding advance care planning in patient and caregiver experiences of illness, and this was a key component of several of the shared decision-making tools that were evaluated for effectiveness.
- Time constraints, resources, and integration into workflow were raised as concerns in implementation; all shared decision-making tools involved additional personnel and resources.

Key Question 4. What educational resources are available for nonpalliative care clinicians about integrating palliative care in ambulatory settings, and what is the evidence for their effectiveness and implementation?

- Although a variety of relevant clinician education and training resources for nonpalliative care clinicians are available, only one implementation study explicitly evaluated this component, and only one effectiveness study included this component.
- Both clinician/stakeholder and patient/caregiver Key Informants expressed that more education and training is needed for ambulatory care clinicians; patients/caregivers indicated that listening skills are especially important.

Key Question 5. What are the models for integrating palliative care into ambulatory settings, and what is the evidence for their effectiveness and implementation?

- The models evaluated for integrating palliative were not more effective than usual care for patient health-related quality of life (strength of evidence [SOE]: Moderate).
- The models evaluated for integrating palliative care may have little to no effect compared with usual care for overall symptom burden (SOE: Low) and were not more effective than usual care for depressive symptom scores (SOE: Moderate).
- The models evaluated for integrating palliative care may have little to no effect compared with usual care on patient satisfaction (SOE: Low), and no studies addressed caregiver satisfaction.
- The models evaluated for integrating palliative care were more effective than usual care for increasing advance directive documentation (SOE: Moderate).
- For utilization, the models evaluated for integrating palliative were not more effective than usual care for reducing hospitalizations; we were unable to draw conclusions about most other aspects of utilization or cost and resource use.

- Multimodal interventions may have little to no effect on increasing advance directive documentation (SOE: Low), and no studies addressed the effect of multimodal interventions for other critical (graded) outcomes.
- Multimodal interventions (including combinations of identification of patients, education for patients and caregivers, shared decision-making tools, and education for nonpalliative care clinicians) had little to no effect on advance directive documentation (SOE: Low) and no studies addressed the effect of multimodal interventions for other critical (graded) outcomes.
- A wide variety of components, characteristics, and factors have been implemented in models for integrating palliative care and are perceived as important by patients, caregivers, clinicians, and stakeholders, but we were unable to draw conclusions about which, if any, of these influence effectiveness or implementation.
- Clinician/stakeholder Key Informants had a number of suggestions for implementation of models and multimodal interventions for integrating palliative care, including integration into and simplification of workflows and documentation, leveraging delivery systems and payment mechanisms, use of interdisciplinary care, and integrating quality measurement and improvement.
- Patient/caregiver Key Informants indicated that clinicians should integrate palliative care into routine care, and that primary care is a key opportunity to introduce it.

Strengths and Limitations

The studies evaluating the effectiveness and implementation of shared decision-making tools focused only on aspects of advance care planning, and included a wide variety of shared tools and models for integrating palliative care across primary care and specialty settings. Studies addressed primary care and common serious illnesses, but none addressed the important ambulatory palliative care issues of multimorbidity or frailty or issues of health equity. Although Web resources exist for identification of patients, patient and caregiver educational materials, and clinician education and training, little evidence for effectiveness or implementation exists for these types of interventions. Key study limitations included issues with blinding of outcomes assessment and variations in outcome reporting (particularly for cost and resource use) in quantitative studies and lack of sufficient rigor in qualitative studies. No studies reported burdens or adverse effects of interventions. Although implementation evidence describes key components and characteristics of models for integrating palliative care and factors in shared decision-making tool and model implementation, evidence for patient/caregiver perspectives on factors in model implementation was limited and we were unable to draw conclusions on the effectiveness of specific components and characteristics, or in specific populations or settings.

Implications and Conclusions

For integrating palliative care into ambulatory care, shared decision-making tools may increase patient satisfaction and advance directive documentation. Models for integrating palliative care may have little to no effect on overall symptom burden and were not effective for patient health-related quality of life or depressive symptom scores, but did increase advance directive documentation. Given the investments needed for these types of interventions with little to no effectiveness for patient-centered outcomes, more research is particularly needed on the effectiveness on patient outcomes of identification of patients for palliative care; educational

materials for patients, caregivers, and clinician; and specific types, components, and characteristics of models for integrating palliative care.

Introduction

Background

Most care for adults with serious life-threatening chronic illness or conditions occurs in ambulatory settings, particularly in clinicians' offices. Care for these patients can be complex, because patients often experience high symptom burden and other needs and decreased health-related quality of life. Patients may benefit from integration of palliative care into ambulatory care, either through the incorporation of palliative care services or by training ambulatory care clinicians in palliative care competencies. Palliative care can be defined as "care, services, or programs for patients with serious life-threatening illness and their caregivers, with the primary intent of relieving suffering and improving health-related quality of life, including dimensions of physical, psychological/ emotional, social, and spiritual well-being."[1] Palliative care interventions aim to address outcomes such as patient symptoms; advance care planning and goals of care communication; patient and caregiver satisfaction; and potentially burdensome healthcare utilization, such as hospitalizations.

Populations with serious life-threatening chronic illness and conditions of key interest for palliative care include, but are not limited to, those with advanced heart failure [New York Heart Association (NYHA) class III or IV], advanced chronic obstructive pulmonary disease [Global Initiative for Chronic Obstructive Lung Disease (GOLD) stage III or IV], end-stage renal disease (older patients on dialysis or choosing not to have dialysis), and those with frailty or multiple serious chronic conditions.[2] Cancer is also a key area of interest for integrating palliative care but, because an existing recent systematic review already addresses integrating palliative care into ambulatory oncology, this review focuses on other illnesses and conditions.[3]

The key decisional dilemma for health systems, clinicians, patients, and family caregivers (noted hereafter as "caregivers") is the following: "How can people with serious life-threatening chronic illness or conditions best receive ambulatory care that integrates appropriate palliative care approaches?" Given the significant investments and competing needs for health systems and clinicians in palliative care along with the costs and burdens for patients and caregivers, the evaluation of patient- and caregiver-centered outcomes, utilization, costs, and burden is important. A variety of types of interventions can be implemented, separately or together, to better integrate palliative care into ambulatory care for this population.

Interventions

Identification of patients. Approaches to identifying ambulatory patients who could benefit from palliative care include triggers or prediction models or tools.[4] These approaches may incorporate patient or illness characteristics; recent hospitalizations; indicators of serious illness or worsening of illness, such as worsening functional status; or patient-reported measures to identify patients who may have needs that could be addressed with palliative care approaches.

Patient and caregiver educational materials and resources. Educational materials about integrating palliative care and palliative care options in ambulatory care such as pamphlets, Web sources, and videos are available from a variety of organizations focusing on palliative care as well as specific conditions. Some evidence supports the effectiveness of patient education for increasing patient acceptance of palliative care.[5]

Shared decision-making tools. Shared decision-making tools are patient-facing and/or clinician-facing tools to help people make decisions for domains such as advance care planning

or symptom management for relevant populations in ambulatory care.[6] Advance care planning, or communication about serious illness care goals, is defined by the American College of Physicians as a key task in ambulatory care that should occur throughout the course of a serious illness.[2] Relevant tools may include advance care planning guides, such as advance directive forms, patient and clinician educational materials, and Web- and video-based interventions focused on serious illness and conditions.

Clinician education. National palliative care organizations and other types of organizations have developed trainings and education materials that include content about integrating palliative care into ambulatory care to educate both palliative care and nonpalliative care clinicians.

Models for integrating palliative care into ambulatory care and multimodal interventions. Successful models for integrating palliative care approaches with primary and other ambulatory care address 1) the complexity of care and needs in cases of serious illness and 2) coordination with broader health systems.[7] Key models for integrating palliative care include shared care (where palliative care clinicians work together with other ambulatory clinicians to meet patients' palliative care needs), consultative care (where nonpalliative care ambulatory clinicians address common palliative care needs, with referrals to specialty palliative care when needs are more complex or are not being met), and the use of supplementary care coordinators or social workers in care. Multimodal interventions, for the purposes of this review, are defined as combinations of the different types of included specific interventions: identification of patients, education for patients and caregivers, shared decision-making tools, and education for nonpalliative care clinicians.

Purpose of the Review

We addressed five questions about the integration of palliative care in ambulatory care for patients with serious life-threatening chronic illness or conditions other than cancer:

1. How can we identify those patients who could benefit from palliative care in ambulatory care settings?
2. What educational resources are available for patients and caregivers in ambulatory care about palliative care?
3. What palliative care decision-making tools are available for clinicians, patients, and caregivers in ambulatory care?
4. What educational resources are available for nonpalliative care clinicians about palliative care in ambulatory settings?
5. What are the models for integrating palliative care into ambulatory settings?

For each of these questions we addressed three parts:

- What is available?
- What is the effectiveness?
- How is it implemented?

Methods

Review Approach

This mixed methods review includes a grey literature search and systematic reviews of the published quantitative and qualitative, mixed-methods, and process evaluation literature, as well as an integration of results across these sources and review methods. We followed the methods outlined in the Agency for Healthcare Research and Quality's (AHRQ's) Methods Guide for Effectiveness and Comparative Effectiveness Reviews (refer to the Methods Appendix for additional details). We have reported the results of the systematic review in accordance with the Preferred Items for Reporting in Systematic Reviews and Meta-Analyses (PRISMA).[8] Integrative review methods are based on the 2017 Cochrane guidance, *Qualitative and Implementation Methods Group Guidance Paper 5: Methods for integrating qualitative and implementation evidence within intervention effectiveness reviews*,[9] and the Joanna Briggs Institute methods for mixed methods systematic reviews.[10]

AHRQ developed the topic of this systematic review. We recruited Key Informants (KIs) to refine the topic and Key Questions and provide input on the integration of results. We recruited a Technical Expert Panel (TEP) to provide input on all details of the protocol, including outcomes. The KIs and TEP represented palliative care, primary care, and other ambulatory specialties, and included physicians, nurses, and social workers; we also included patient advocate KIs. With the feedback from the TEP, KIs, AHRQ, and our partners, the National Institute for Nursing Research, and the Health Resources and Services Administration, we finalized the protocol and posted it on the AHRQ Effective Health Care Program's website (www.effectivehealthcare.ahrq.gov).

Key Questions

Key Question (KQ) 1. How can we identify those patients who could benefit from palliative care in ambulatory care settings, and what is the evidence for effectiveness and implementation of these methods?

KQ1a. What prediction models, tools, triggers, and guidelines and position statements are available about how to identify when and which patients with serious life-threatening chronic illness or conditions in ambulatory settings could benefit from palliative care?

KQ1b. What is the effectiveness of prediction models, tools, and triggers for identifying when and which patients with serious life-threatening chronic illness or conditions in ambulatory settings could benefit from palliative care?

KQ1c. How have prediction models, tools, and triggers for identifying when and which patients with serious life-threatening chronic illness or conditions in ambulatory settings could benefit from palliative care been implemented? What is the evidence for how, when, and for which patients they could best be implemented in care?

Key Question 2. What educational resources are available for patients and caregivers in ambulatory care about integrating palliative care, and what is the evidence for their effectiveness and implementation?

KQ2a. What educational materials and resources are available about palliative care and palliative care options for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers?

KQ2b. What is the effectiveness of educational materials and resources about palliative care and palliative care options for patients with serious life-threatening chronic illness or conditions and their caregivers in ambulatory settings?

KQ2c. How have educational materials and resources about palliative care and palliative care options for patients with serious life-threatening chronic illness or conditions and their caregivers in ambulatory settings been implemented? What is the evidence for how, when, and for which patients and caregivers they could best be implemented in care?

Key Question 3. What palliative care shared decision-making tools for serious life-threatening chronic illness or conditions are available for clinicians, patients, and caregivers in ambulatory care, and what is the evidence for their effectiveness and implementation?

KQ3a. What palliative care shared decision-making tools are available for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers?

KQ3b. What is the effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers?

KQ3c. How have palliative care shared decision-making tools been implemented for patients with serious life-threatening chronic illness or

conditions in ambulatory settings and their caregivers? What is the evidence for how, when, and for which patients and caregivers they could best be implemented in care?

Key Question 4. What educational resources are available for nonpalliative care clinicians about integrating palliative care in ambulatory settings, and what is the evidence for their effectiveness and implementation?

KQ4a. What palliative care training and educational materials are available for nonpalliative care clinicians caring for patients with serious life-threatening chronic illness or conditions in ambulatory settings?

KQ4b. What is the effectiveness of palliative care training and educational materials (with or without other intervention components) for nonpalliative care clinicians caring for patients with serious life-threatening chronic illness or conditions in ambulatory settings?

KQ4c. How have palliative care training and educational materials (with or without other intervention components) for nonpalliative care clinicians caring for patients with serious life-threatening chronic illness or conditions in ambulatory settings been implemented? What is the evidence for how, when, and for which clinicians they could best be implemented in care?

Key Question 5. What are the models for integrating palliative care into ambulatory settings, and what is the evidence for their effectiveness and implementation?

KQ5a. What models and multimodal interventions for integrating palliative care have been developed for patients with serious life-threatening chronic illness or conditions in ambulatory settings?

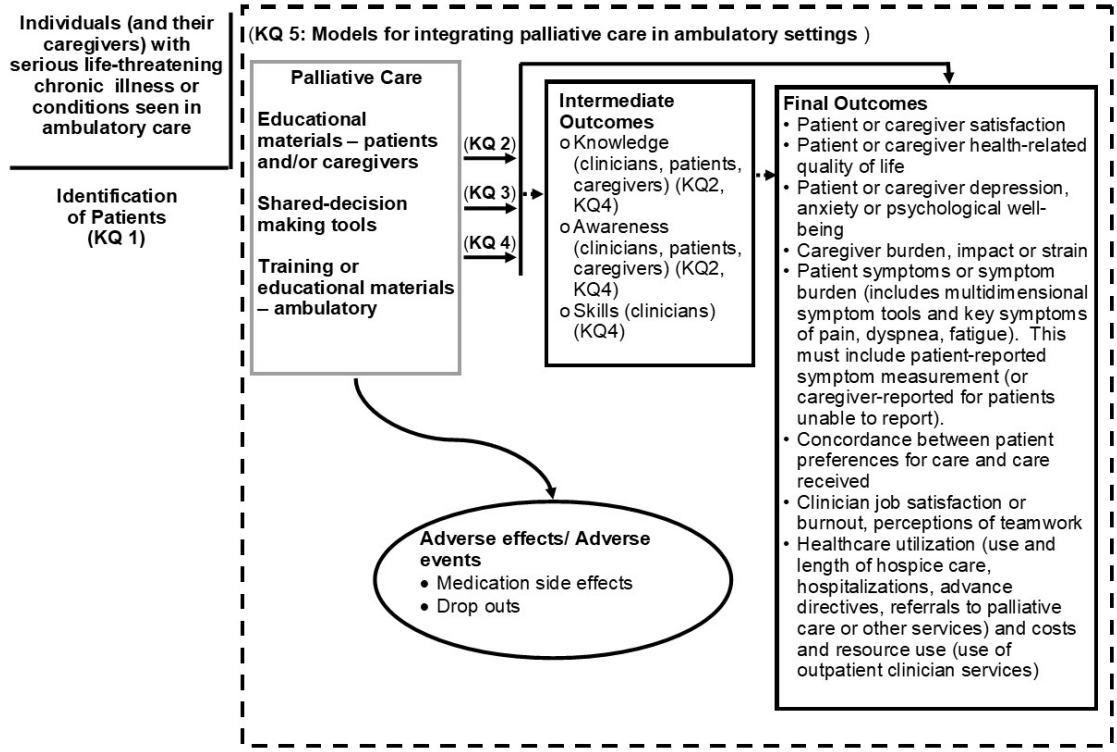
KQ5b. What is the effectiveness of models and multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings?

KQ5c. What are components of models and multimodal interventions for integrating palliative care in ambulatory settings? What models and multimodal interventions have been implemented for key subpopulations? What components and characteristics of these models and multimodal interventions contribute to their effective implementation? What is the evidence for how, when, and for which patients they could best be implemented in care?

Analytic Framework

Figure 1 displays the analytic framework. With input from the stakeholders and experts, we considered effectiveness as those outcomes that are within the domains of palliative care and have evidence for associations with patient and caregiver outcomes.

Figure 1. Analytic framework for integrating palliative care in ambulatory care of noncancer serious chronic illness



KQ = Key Question

Study Selection

We searched PubMed®, CINAHL®, and the Cochrane Central Register of Controlled Trials in May 2020. Two team members independently applied eligibility criteria (Table 1 and Table 2) to citations identified by these searches. In March 2020, we searched key U.S. national websites identified as relevant to the Key Questions and refined with input from AHRQ and Technical Experts, including websites from palliative care organizations, primary care and specialty healthcare professional organizations, government organizations, foundations with a major focus in palliative care, and patient organizations (see Methods Appendix A for full list of websites searched). Two reviewers simultaneously screened available website content for eligibility based on the Population, Intervention, Comparisons, Outcomes, Type of study, Setting (PICOTS); specific relevance to integrating palliative care into ambulatory care in the United States; and our criterion that materials must have been developed or updated within the last 5 years. Full details on the search strategy and eligibility criteria are in Methods Appendix A.

Table 1. PICOTS: Inclusion and exclusion criteria for quantitative studies relevant to integrating palliative care into ambulatory care for serious life-threatening chronic illness or conditions

PICOTS	Inclusion	Exclusion
Population	• Patients (≥18 years of age) with serious life-threatening chronic illness or conditions (other than those only with cancer) and their caregivers, being seen in ambulatory settings (KQs 1,2,3,5) • Clinicians practicing in ambulatory settings (KQ4)	• Studies with only cancer patients • Studies not focusing on ambulatory populations • Studies of clinicians caring only for cancer patients • Studies focusing on trainees
Interventions	KQ1: prediction models, tools, or triggers to identify patients for palliative care in ambulatory settings KQ2: educational materials and resources about palliative care for patients and/or caregivers in ambulatory settings KQ3: palliative care shared decision-making tools and resources for clinicians and patients and/or caregivers in ambulatory settings KQ4: palliative care training or educational materials for ambulatory settings KQ5: models for integrating palliative care or multimodal interventions in ambulatory settings	• Studies that report no intervention of interest
Comparisons	KQ1: prediction models, tools, or triggers to identify patients for palliative care in ambulatory settings KQ2: educational materials and resources about palliative care for patients and/or caregivers in ambulatory settings KQ3: palliative care shared decision-making tools and resources for clinicians and patients and/or caregivers in ambulatory settings KQ4: palliative care training or educational materials for ambulatory settings KQ5: models for integrating palliative care or multimodal interventions in ambulatory settings Usual care for all KQs	• Studies that do not report the comparisons of interest*

PICOTS	Inclusion	Exclusion
Outcomes	Intermediate • Knowledge (clinicians, patients, caregivers) (KQ2, KQ4) • Awareness (clinicians, patients, caregivers) (KQ2, KQ4) • Skills (clinicians) (KQ4) Final (All apply to all KQ) (In hierarchy from patient-centered to clinician to health system. All patient- or caregiver-reported outcomes must be measured by a validated instrument.[11]) • Patient or caregiver satisfaction • Patient or caregiver health-related quality of life • Patient or caregiver symptoms of depression, anxiety, or psychological well-being • Caregiver burden, caregiver impact, or caregiver strain • Patient symptoms or symptom burden (includes multidimensional symptom tools and key symptoms of pain, dyspnea, fatigue); this must include patient-reported symptom measurement (or caregiver-reported for patients unable to report) • Concordance between patient preferences for care and care received • Clinician job satisfaction or burnout, perceptions of teamwork • Healthcare utilization (use and length of hospice care, hospitalizations, advance directive documentation) and costs and resource use (use of outpatient clinician services, including palliative care) Adverse effects • Medication side effects • Dropouts related to the intervention	• Studies that do not report the outcomes of interest • Excludes clinician self-report for intermediate outcomes
Type of Study	• Randomized controlled trials • Non-randomized studies with concurrent controls or historical controls ((controlled trials or prospective cohort studies)	• Articles published prior to the year 2000 • Non-English publications • Case reports or case series • Publications with no original data (e.g., editorials, letters, comments, reviews) • Full text not presented or unavailable, abstracts only
Timing and Setting	• Any timing • Ambulatory care settings • U.S.-based studies	• Hospital setting • Oncology setting • Emergency department • Nursing home and long-term care facilities

*Comparisons to other included interventions or to usual care.
PICOTS= Population, Intervention, Comparisons, Outcomes, Type of study, Setting; KQ=Key Questions

Table 2. Additional inclusion and exclusion criteria for qualitative, mixed-methods, and process evaluation studies

Criteria	Inclusion	Exclusion
Comparison	No comparison group needed	No exclusion
Type of study	• Systematic reviews of qualitative studies • Qualitative or mixed-methods studies: including studies that use a formal qualitative data collection method (e.g., interviews, focus groups, ethnography) and analysis methods (e.g., phenomenological, grounded theory, ethnographic and thematic analysis studies) • Process evaluation studies (type of implementation studies) including studies that address the following in results: o Identifying/addressing barriers/facilitators o Populations to target o Mechanisms for success/failure	• Qualitative studies: observation or artifact analysis • Process evaluation studies focusing only on research issues (e.g., fidelity, participant recruitment, intervention quality, participant engagement)
Sample size		• Analysis of interest includes fewer than 10 participants

Data Extraction and Risk of Bias Assessment

Paired investigators abstracted data sequentially. For quantitative studies, reviewers assessed risk of bias independently. We used the Cochrane Risk of Bias Tool, Version 2, for assessing the risk of bias of randomized controlled trials (RCTs).[12] For non-randomized studies, we used the Cochrane Risk of Bias Assessment Tool for Non-Randomized Studies of Interventions (ROBINS-I) tool.[13] For qualitative and mixed-methods studies, reviewers independently assessed study quality using the Joanna Briggs Institute Checklist[14, 15] (see Methods Appendix A for more details).

In addition to seeking feedback from the Key Informants on the Key Questions, we engaged two separate groups of Key Informants to provide input on the integrative review process: one group of patients and caregivers; and one group of stakeholders, including practicing clinicians, relevant professional and consumer organizations, purchasers of healthcare, representatives of Learning Health Systems, and others with experience making healthcare decisions. We compiled key issues elicited from the Key Informants and used those to inform our analysis of the qualitative, mixed-methods, and process evaluation literature and the overall integration. At the end of the project, we also conducted sessions with the Key Informants to refine the analysis and integration results.

Data Synthesis and Analysis

We organized the report by Key Question and sub-question. We conducted descriptive synthesis for each Key Question. We conducted meta-analyses when there were sufficient data (i.e., at least three studies) and studies were sufficiently similar with respect to key variables (e.g., population characteristics, study duration, intervention, and outcome measures). When appropriate, we standardized results by estimating the standardized mean difference using the Cohen d method. We used STATA statistical software (Intercooled, version 14, StataCorp, College Station, TX) for all meta-analyses (see Appendix A for details).

We determined clinically meaningful differences for outcome measures wherever possible (see Methods Appendix A for additional details).

We conducted a mixed-methods review in which we completed separate reviews of the different types of evidence, first, and then integrated those results. We completed integration by juxtaposing the findings from a) what is available; with b) the systematic review of quantitative studies (effectiveness); and c) the systematic review of qualitative, mixed-methods, and process evaluation studies (implementation). We used frameworks based on the Consolidated Framework for Implementation From MFResearch adapted for complex interventions and input from the Key Informants (see Methods Appendix A for additional details).[16]

Grading the Strength of the Body of Evidence

We graded the strength of evidence for the systematic review of quantitative studies using the grading scheme recommended by the AHRQ Guide for Conducting Comparative Effectiveness Reviews.[17] We applied evidence grades for the outcomes we classified, with input from our TEP panel, as critical during protocol development, including patient health-related quality of life, patient symptom burden, patient symptoms of depression, patient satisfaction, caregiver satisfaction, and advance directive documentation (see the Methods Appendix A for details regarding the domains assessed, the processes for determining the grades, and the definitions of each grade).

Results

Search Results

We included 46 Web resources specifically addressing integrating palliative care into ambulatory care from the pre-defined key U.S. national websites, 20 quantitative effectiveness studies (n=5,004), and 16 qualitative implementation studies (n>224); we did not identify any mixed-methods studies (see Appendix B for listing of excluded Web resources and studies; Appendix C for listing of included U.S. national Web resources and studies; Appendix Figure C-1 through Figure C-3 for details on the results of the searches and Appendix Table C-1 for summary of key points from Key Informant interviews; and Appendix D for details on the studies, including characteristics of studies and interventions, risk of bias or quality, and strength of evidence).

Below, we summarize parts a, b, and c of each Key Question: what is available, the review of the quantitative effectiveness studies, and the review of the qualitative implementation studies. Finally, we present the integration of these three reviews as well as the patient/caregiver and clinician/stakeholder Key Informant input. We found no studies solely addressing effectiveness of prediction models, tools, or triggers (Key Question 1b), patient and caregiver educational resources (Key Question 2b), or educational resources for clinicians (Key Question 4b). We also found no studies assessing implementation of prediction models, tools, or triggers (Key Question 1c) or patient/caregiver educational resources (Key Question 2c) (see Table 3). Finally, we found no studies addressing the critical outcome of overall patient symptom burden.

Table 3. Resources and studies included in the review*

Intervention Type	Web Resources	Quantitative Effectiveness Studies	Qualitative Implementation Studies
Prediction models, tools, triggers, guidelines and position statements	14	0	0
Patient/ caregiver educational materials and resources	13	0	0
Shared decision-making tools	5	6	5
Nonpalliative care clinician training and educational materials	12	0	1
Models for integrating palliative care Multimodal interventions	2 0	12 2	9 1
Total	46	20	16

*Two multimodal intervention effectiveness studies included shared decision-making tools and triggers: one model effectiveness study included a significant patient education component, and one model effectiveness study included a significant clinician education component.

Key Subquestion a. What Is Available?

For each Key Question below, we describe included Web resources from the key U.S. national websites and effectiveness or implementation studies relevant to integration of palliative care into ambulatory care for patients with serious life-threatening chronic illness or conditions (see Appendix B for listing of excluded Web resources and studies and Appendix C for listing of included Web resources and studies, and tables 4-8 below list included Web resources).

Key Question 1a. What prediction models, tools, triggers, and guidelines and position statements are available about how to identify when and which patients with serious life-threatening chronic illness or conditions in ambulatory settings could benefit from palliative care?

Table 4. What is available: patient identification (prediction models, tools, and triggers) and guidelines and position statements for integrating palliative care into ambulatory care for patients with serious life-threatening chronic illness or conditions

Type	Content Focus	Name of Specific Resource/Intervention	Illness or Condition/Setting	Type of Resource	Organization	Cost
Web resouces	Patient Identification*	LACE Index Scoring Tool for Risk Assessment of Hospital Readmission[18] https://www.capc.org/toolkits/patient-identification-and-assessment/	Community-based setting	Print	Center to Advance Palliative Care	Free to members
	Patient Identification*	Charlson Comorbidity Index[18] https://www.capc.org/toolkits/patient-identification-and-assessment/	Community-based setting	Print	Center to Advance Palliative Care	Free to members
	Patient Identification*	Clinical Triggers for PCMH Referral to Palliative Care[18] https://www.capc.org/toolkits/patient-identification-and-assessment/	Community-based setting	Print	Center to Advance Palliative Care	Free to members
	Patient Identification*	Supportive and Palliative Care Indicators Tool (SPICT™)[18] https://www.capc.org/toolkits/patient-identification-and-assessment/	Community-based setting	Print	Center to Advance Palliative Care	Free to members
	Patient Identification*	Walter Prognostic Index[18] https://www.capc.org/toolkits/patient-identification-and-assessment/	Community-based setting	Print	Center to Advance Palliative Care	Free to members
	Patient Identification*	Comprehensive ICD-10 Codes to Capture Patients with Serious Illness[18] https://www.capc.org/toolkits/patient-identification-and-assessment/	Community-based setting	Inaccessible	Center to Advance Palliative Care	Free to members
	Patient Identification*	Communicating with Treating Clinicians about the Implications of Frailty[18] https://www.capc.org/toolkits/patient-identification-and-assessment/	Inaccessible	Inaccessible	Center to Advance Palliative Care	Free to members

Type	Content Focus	Name of Specific Resource/Intervention	Illness or Condition/Setting	Type of Resource	Organization	Cost
	Patient Identification*	Identifying the Right Patients for Specialty[18] https://www.capc.org/toolkits/patient-identification-and-assessment/	Inaccessible	Video	Center to Advance Palliative Care	Free to members
	Patient Identification*	Patient Engagement Guide[18] https://www.capc.org/toolkits/patient-identification-and-assessment/	Inaccessible	Inaccessible	Center to Advance Palliative Care	Free to members
	Guidelines	Clinical Practice Guidelines for Quality Palliative Care[19] https://www.nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf	General	Print	National Coalition for Hospice and Palliative Care	Free
	Guidelines	Integrating Palliative Care and Symptom Relief into Primary Health Care[20] https://apps.who.int/iris/bitstream/handle/10665/274559/9789241514477-eng.pdf?ua=1	General	Print	World Health Organization	Free
	Position Statements	End-of-Life Care[21] https://www.alz.org/media/Documents/end-of-life-care-statement.pdf	General	Print	Alzheimer's Association	Free
	Position Statements	Nephrology Nurse's Role in Palliative and End-of-Life Care[22] https://www.annanurse.org/download/reference/health/position/palliativeCare.pdf	ESRD	Print	American Nephrology Nurses Association	Free
	Position Statements	Advance Care Planning[23] https://advancingexpertcare.org/position-statements	General	Print	Hospice and Palliative Nurses Association	Free
Effectiveness studies	Multimodal interventions** Patient identification	Serious Illness Program[24, 25]	General	Part of intervention	N/A	N/A
	Multimodal interventions** Patient identification	Implantable cardioverter-defibrillator deactivation[26]	Heart failure	Part of intervention	N/A	N/A
Implementation studies	None identified	None identified	None identified	None identified	None identified	None identified

LACE = length of stay, acuity of admission, comorbidities, emergency department visits; PCMH = patient-centered medical home; SPICT = Supportive and Palliative Care Indicators Tool; ICD-10 = International Classification of Diseases, Tenth Revision; N/A = not applicable.
*Patient identification tools included are those compiled by the Center to Advance Palliative Care in their Patient Identification and Assessment toolkit for Community-Based Providers in their Web resource but were not developed by this organization.
**Multimodal interventions listed with both components (i.e., here and under shared decision-making tools) as well as under multimodal (KQ5).

Key Question 2a. What educational materials and resources are available about palliative care and palliative care options for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers?

Table 5. What is available: patient and caregiver educational materials for integrating palliative care into ambulatory care for patients with serious life-threatening chronic illness or conditions

Type	Content Focus	Name of Specific Resource/Intervention	Illness or Condition/ Setting	Type of Resource	Organization	Cost
Web resources	Advance Care Planning	COPD Action Plan[27] https://www.lung.org/getmedia/c7657648-a30f-4465-af92-fc762411922e/fy20-ala-copd-action-plan.pdf	COPD	Print	American Lung Association	Free
	Advance Care Planning	10 FAQs: Medicare's Role in End-of-Life Care[28] https://www.kff.org/medicare/fact-sheet/10-faqs-medicares-role-in-end-of-life-care/	General	Print	Kaiser Family Foundation	Free
	Advance Care Planning	Getting your Affairs in Order[29] https://www.nia.nih.gov/health/getting-your-affairs-order	General	Web page	National Institute on Aging	Free
	Advance Care Planning	Legal and Financial Planning for People with Alzheimer's[30] https://www.nia.nih.gov/health/legal-and-financial-planning-people-alzheimers	Dementia	Web page	National Institute on Aging	Free
	General Information	What Caregivers Should Know About Palliative Care[31] https://www.aarp.org/caregiving/health/info-2019/palliative-care.html	General	Web pages	American Association for Retired Persons	Free
	General Information	Training Curriculum: Alzheimer's Disease and Related Dementias For Caregivers Module 2. Caregiver Role in Shared Decision-Making[32] https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum	Dementia	Module with printable guide	Health Resources & Services Administration	Free
	General Information	Palliative Care for People with Respiratory Disease or Critical Illness[33] https://www.thoracic.org/patients/patient-resources/resources/palliative-care.pdf	COPD	Print	American Thoracic Society	Free
	General Information	Palliative Care: The Relief You Need When You Have a Serious Illness[34] https://www.ninr.nih.gov/sites/files/docs/palliative-care-brochure.pdf	General	Print	National Institute of Nursing Research	Free
	General Information	Cuidados Paliativos: El alivio que necesita cuando tiene una enfermedad grave[35] https://www.ninr.nih.gov/sites/files/docs/cuidadospaliativos.pdf	General	Print	National Institute of Nursing Research	Free

Type	Content Focus	Name of Specific Resource/Intervention	Illness or Condition/ Setting	Type of Resource	Organization	Cost
	General Information	What is Palliative Care?[36] https://www.ninr.nih.gov/newsandinformation/what-is-palliative-care	General	Web page	National Institute of Nursing Research	Free
	General Information	What Are Palliative Care and Hospice Care?[37] https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care	General	Web page	National Institute on Aging	Free
	General Information	Get Palliative Care[38] https://getpalliativecare.org	General	Web page	Center to Advance Palliative Care	Free
	General Information	Palliative Care Helps Patients with Kidney Disease[39] https://www.kidney.org/atoz/content/palliative-care-helps-patients-kidney-disease	ESRD	Web page	National Kidney Foundation	Free
Effectiveness studies	None identified	None identified	None identified	None identified	None identified	None identified
Implementation studies	None identified	None identified	None identified	None identified	None identified	None identified

COPD = chronic obstructive pulmonary disease; ESRD = end-stage renal disease.

Key Question 3a. What palliative care shared decision-making tools are available for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers?

Table 6. What is available: shared decision-making tools for integrating palliative care into ambulatory care for patients with serious life-threatening chronic illness or conditions

Type	Content Focus	Name of Specific Resource/Intervention	Illness or Condition/ Setting	Type of Resource	Organization	Cost
Web resources	Advance care planning	Planning Today for Tomorrow's Healthcare: A Guide for People with Chronic Kidney Disease[40] https://cpb-us-w2.wpmucdn.com/blogs.nursing.gwu.edu/dist/a/4/files/2019/05/ACPforCKDbrochure4302018Web.pdf	ESRD	Print	Coalition for Supportive Care of Kidney Patients	Free
	Advance care planning	The POLST Form[41] https://cpb-us-w2.wpmucdn.com/blogs.nursing.gwu.edu/dist/a/4/files/2019/05/POLST_Form.pdf	General	Print	Coalition for Supportive Care of Kidney Patients	Free
	Advance care planning	Advance Care Planning: Healthcare Directives[42] https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives	General	Web page, print, video	National Institute on Aging	Free

Type	Content Focus	Name of Specific Resource/Intervention	Illness or Condition/ Setting	Type of Resource	Organization	Cost
	Advance care planning	End of Life Planning[43] https://www.alz.org/help-support/i-have-alz/plan-for-your-future/end_of_life_planning	Dementia	Web pages	Alzheimer's Association	Free
	Advance care planning	Planning for Advanced Heart Failure[44] https://www.heart.org/en/health-topics/heart-failure/living-with-heart-failure-and-managing-advanced-hf/planning-ahead-advanced-heart-failure	Heart failure	Web pages	American Heart Association	Free
Effectiveness studies	Advance care planning	Jumpstart-Tips (2 studies)[45,46]	lung cancer, COPD, heart failure, cirrhosis, ESRD	Print	N/A	N/A
	Advance care planning	Palliative Care - Advance Care Planning[47]	Heart failure or ESRD	Interview	N/A	N/A
	Advance care planning	Advance directives guide or Peer mentoring[48]	ESRD	Print or in-person	N/A	N/A
	Advance care planning	Sharing Patients' Illness Representation to Increase Trust[49]	ESRD	Interview	N/A	N/A
	Multimodal interventions* Advance care planning	Serious Illness Program[24, 25]	General	Part of intervention	N/A	N/A
	Multimodal interventions* Advance care planning	Implantable cardioverter-defibrillator deactivation[26]	Heart failure	Part of intervention	N/A	N/A
Implementation studies	Advance care planning	Informed Together[50]	COPD	Web-based	N/A	N/A
	Advance care planning	Sharing Patients' Illness Representation to Increase Trust (2 studies)[51,52]	ESRD, heart failure	Interview	N/A	N/A

POLST = Provider Orders for Life-Sustaining Treatment; ESRD = end-stage renal disease; COPD = chronic obstructive pulmonary disease; N/A = not applicable.
*Multimodal intervention listed with both components (i.e., here and under triggers).

Key Question 4a. What palliative care training and educational materials are available for nonpalliative care clinicians caring for patients with serious life-threatening chronic illness or conditions in ambulatory settings?

Table 7. What is available: training and educational materials for nonpalliative care clinicians on integrating palliative care into ambulatory care for patients with serious life-threatening chronic illness or conditions

Type	Content Focus	Name of Specific Resource/Intervention	Illness or Condition/ Setting	Type of Resource	Organization	Cost
Web resources	Advance Care Planning	Educate and Train Professionals[53] https://www.alz.org/professionals/public-health/core-areas/educate-train-professionals	Dementia	Web page	Alzheimer's Association	Free
	Advance Care Planning	Advanced Care Planning[54] https://www.kidneysupportivecare.org/advanced-care-planning/	ESRD	Web page	Coalition for Supportive Care of Kidney Patients	Free
	Advance Care Planning	Curriculum Guide for Advance Care Planning[55] https://cpb-us-w2.wpmucdn.com/blogs.nursing.gwu.edu/dist/a/4/files/2019/05/CurriculumGuideAdvanceCarePlan4302018bWeb.pdf	ESRD	Print	Coalition for Supportive Care of Kidney Patients	Free
	Advance Care Planning	Improving Advance Care Planning: Research Results from the "Conversation Starters" Focus Groups and "Conversation Stopper" Physician Survey[56] https://www.johnahartford.org/dissemination-center/view/advance-care-planning-poll	General	Web page	Hartford Foundation	Free
	Advance Care Planning	Pew Glossary: Improving End-of-Life Care[57] https://www.pewtrusts.org/en/research-and-analysis/fact-sheets/2015/05/pew-glossary-improving-end-of-life-care	General	Web page	Pew Charitable Trusts	Free
	Advance Care Planning	Capturing Treatment Preferences for End-of-Life Care[58] https://www.pewtrusts.org/en/research-and-analysis/fact-sheets/2015/12/capturing-treatment-preferences-for-end-of-life-care	General	Web page	Pew Charitable Trusts	Free
	Advance Care Planning	Documenting End-of-Life Wishes With Physician Orders for Life-Sustaining Treatment[59] https://www.pewtrusts.org/-/media/assets/2016/07/documentingendoflifewisheswithphysicianordersforlifesustainingtreatmentpolstparadigm.pdf	General	Web page	Pew Charitable Trusts	Free
	Advance Care Planning	POLST Paradigm[59] https://www.pewtrusts.org/-/media/assets/2016/07/documentingendoflifewisheswithphysicianordersforlifesustainingtreatmentpolstparadigm.pdf	General	Print	Pew Charitable Trusts	Free

Type	Content Focus	Name of Specific Resource/Intervention	Illness or Condition/ Setting	Type of Resource	Organization	Cost
	General Information	Defining Hope[60] https://hope.film/study-guide-videos/	General	14 videos, print	American Nurses Association/ Foundation	Free
	General Information	Downloadable Tools for Making the Case[61] https://www.capc.org/tools-for-making-the-case/downloadable-tools/	General	Web pages, toolkit	Center to Advance Palliative Care	Free to members
	General Information	Supporting the Caregivers of People Living with Dementia[62] https://www.capc.org/training/best-practices-in-dementia-care-and-caregiver-support/supporting-caregivers-people-living-dementia/	Dementia	Toolkit with 13 printable resources	Center to Advance Palliative Care	Free to members
	General Information	Training Curriculum: Alzheimer's Disease and Related Dementias Module 12: Palliative and End of Life Care[32] https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum	Dementia	Modules with printable guide	Health Resources & Services Administration	Free
	General Information	Training Curriculum: Alzheimer's Disease and Related Dementias. For Providers: Module 2: Shared Decision-Making[63] https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum	Dementia	Modules with printable guide	Health Resources & Services Administration	Free
Effectiveness studies	None identified	None identified	None identified	None identified	None identified	None identified
Implementation studies	Advance Care Planning	Serious Illness Conversation Guide[64]	General	Train-the-trainer	N/A	N/A

POLST = Provider Orders for Life-Sustaining Treatment; ESRD = end-stage renal disease.; N/A = not applicable.

Key Question 5a. What models and multimodal interventions for integrating palliative care have been developed for patients with serious life-threatening chronic illness or conditions in ambulatory settings?

Table 8. What is available: models for integrating palliative care into ambulatory care for patients with serious life-threatening chronic illness or conditions*

Type	Content Focus	Name/Description of Specific Resource/Intervention	Illness or Condition/Setting	Type of Resource	Organization	Cost
Web resources	Models	Primary Care First Model Options[65] https://innovation.cms.gov/innovation-models/primary-care-first-model-options	Primary care	Web page	Centers for Medicare & Medicaid Services	Free

Type	Content Focus	Name/Description of Specific Resource/Intervention	Illness or Condition/Setting	Type of Resource	Organization	Cost
	Models	Models and Strategies to Integrate Palliative Care Principles into Care for People with Serious Illness: Proceedings of a Workshop[66] https://www.nationalacademies.org/our-work/models-and-strategies-to-integrate-palliative-care-principles-into-serious-illness-care-a-workshop	Broad range of patient populations, clinical settings	Print	National Academies of Sciences, Engineering, and Medicine	Free
Effectiveness studies	Models	Integrated interdisciplinary palliative care[67]	Parkinson's	Intervention	N/A	N/A
	Models	Primary Palliative Care Clinic[68]	Primary care	Intervention	N/A	N/A
	Models	Palliative Care in Heart Failure[69]	Heart failure	Intervention	N/A	N/A
	Models	Intensive interdisciplinary palliative care consultation[70]	Heart failure	Intervention	N/A	N/A
	Models	Collaborative Care to Alleviate Symptom and Adjust to Illness[71]	Heart failure	Intervention	N/A	N/A
	Models	Patient-Centered Disease Management[72]	Heart failure	Intervention	N/A	N/A
	Models	Integrated physician palliative care[73]	ESRD	Intervention	N/A	N/A
	Models	Comprehensive Care Team[74, 75]	Cancer, COPD, heart failure	Intervention	N/A	N/A
	Models	Advanced Illness Coordinated Care Program (2 studies)[76,77]	COPD, heart failure, end-stage pulmonary disease, ESRD, cancer	Intervention	N/A	N/A
	Models	Social-worker led palliative care[78]	Heart failure	Intervention	N/A	N/A
	Models	Psychosocial and problem-solving support[79]	Heart failure	Intervention	N/A	N/A
	Multimodal interventions *	*Serious Illness Program[24, 25]	General	Part of intervention	N/A	N/A
	Multimodal interventions *	Implantable cardioverter-defibrillator deactivation[26]	Heart failure	Part of intervention	N/A	N/A
Implementation studies	Models	Collaborative Care to Alleviate Symptoms and Adjust to Illness[80]	Heart failure, hypertension, COPD	Intervention	N/A	N/A
	Models	Palliative care[81]	COPD	Intervention	N/A	N/A
	Models	Comprehensive Care Team[82]	COPD, heart failure, cancer	Intervention	N/A	N/A
	Models	Communication intervention[83]	ESRD	Intervention	N/A	N/A
	Multimodal interventions *	Serious Illness Care Program[84]	Primary care	Intervention	N/A	N/A

COPD = chronic obstructive pulmonary disease; ESRD = end-stage renal disease; N/A = not applicable.
*Note that multimodal interventions are also listed under the specific components above.

Key Subquestion b. What Is the Effectiveness?

Key Question 1b. What is the effectiveness of prediction models, tools, and triggers for identifying when and which patients with serious life-threatening chronic illness or conditions in ambulatory settings could benefit from palliative care?

We identified no studies for this Key Question.

Key Question 2b. What is the effectiveness of educational materials and resources about palliative care and palliative care options for patients with serious life-threatening chronic illness or conditions and their caregivers in ambulatory settings?

We identified no studies for this Key Question.

Key Question 3b. What is the effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers?

Key Points

- All shared decision-making tools evaluated addressed advance care planning.
- Advance care planning shared decision-making tools may be effective for improving patient satisfaction with communication compared with usual care (strength of evidence [SOE]: Low).
- Advance care planning shared decision-making tools may be effective for increasing advance directive documentation compared with usual care (SOE: Low).
- We could not draw conclusions about the effect of advance care planning shared decision-making tools on caregiver satisfaction or patient depressive symptom scores, and no studies addressed other critical outcomes.

Six randomized controlled trials (RCTs) assessed the effectiveness of palliative care shared decision-making tools for patients and caregivers in ambulatory settings (Table 10).[45-49, 85] These six studies included 1,567 patients (overall range of mean ages was 19 to 83 years) and 58 caregivers (overall mean age was 48 years). Two studies were conducted with end-stage renal disease (ESRD) patients on dialysis; one with ESRD patients on dialysis or with heart failure; one with chronic obstructive pulmonary disease (COPD) patients; and one with multiple serious illnesses, including lung cancer, COPD, heart failure, cirrhosis, and ESRD (Table 9, see Evidence Tables Appendix D for full study characteristics).

Table 9. Characteristics of effectiveness studies assessing shared decision-making tools

Author, Year	Study Characteristics	Intervention Description	Followup Duration
Curtis, et al., 2018[45]	n=537 • Multi-setting, cluster-randomized trial, academic and community setting, primary and specialty care • Patients with lung cancer, COPD, heart failure, cirrhosis, or ESRD • Government and private funding	• Control Group: Enhanced usual care, which included completion of surveys and regular contact with study personnel. • Intervention: Jumpstart-Tips. Patients completed survey questions to identify preferences, barriers, and facilitators for communication about end-of-life care. Clinicians received information and communication tips based on the survey. Patients also received a summary of the survey and suggestions for having a goals-of-care conversation with the clinician. • Outcomes: Patient satisfaction, symptoms of depression or anxiety, concordance between preferences and care received, and advance directive documentation.	3 months (2 weeks for patient satisfaction)
Au, et al., 2012[46]	n=376 • Multi-setting, cluster-randomized trial, academic and non-teaching centers • Patients with COPD • Government funding	• Control Group: Control group completed questionnaires but did not receive feedback. • Intervention: Patients completed a pre-visit survey addressing preferences, barriers, and facilitators for communication about end-of-life care. Clinicians received a one-page, patient-specific feedback form based on survey responses and communication tips; patients also received a feedback form based on the survey responses. • Outcome: Patient satisfaction.	2 weeks
Kirchhoff, et al., 2012[47]	n=313 • Multi-setting, RCT, academic, community dialysis centers • Patients with heart failure or ESRD, and their caregivers • Government funding	• Control Group: Received usual care; a standard advance directive counseling assessment on admission; and an offering of additional information, if interested. • Intervention: Palliative Care - Advance Care Planning, single interview lasting 1 to 1.5 hours to assess patient and caregiver understanding and experience with illness, assist caregiver in preparing to be a decision-maker, and assist in documentation of patient end-of-life preferences using the Statement of Treatment Preferences. • Outcome: Concordance between patient preferences and care received.	Post-death followup control (19-997 days); intervention (5-1,010 days)

Author, Year	Study Characteristics	Intervention Description	Followup Duration
Perry, et al., 2005[48]	n=203 • Multi-setting, 3-arm RCT, academic, 21 dialysis centers, • Patients with ERSD • Government, non-profit	• Control Group arm 1: No study materials, only routine care provided by the dialysis center. • Intervention arm 2: Printed materials prepared by the National Kidney Foundation ("Advance Directives: A Guide for Patients and Families") distributed within the 2- to 4-month period. • Intervention arm 3: Peer mentoring: 17 peers attended a training workshop to learn about advance directives, assessed through pre-/post-tests and role-playing. Peers contacted patient participants 8 times, which included 5 phone contacts and 3 face-to-face meetings. • Outcome: Advance directive documentation.	2 to 4 months
Song, et al., 2009[49]	n=116 • Multi-Setting, RCT, pre-/post-test, nephrology, community dialysis clinics • Patients with ERSD • Government funding	• Control Group: Received usual care consisting of a clinic social worker providing information on advance directives and rights to have an advance directive on the first day of dialysis treatment. • Intervention: Sharing Patients' Illness Representation to Increase Trust (SPIRIT), up to 1-hour, single session interview with a patient-caregiver dyad, delivered by a trained nurse who received competency-based training for 3.5 days, to enhance communication between patients and caregivers about end-of-life care. • Outcomes: Patient and caregiver satisfaction.	3 months
Doorenbos, et al., 2016 [85]	n=80 • Single Setting, academic heart failure (HF) clinic RCT, 2 group comparison • Patients with heart failure with an ejection fraction (EF)≤ 40% or preserved EF of <50% • Government, non-profit	• Control Group: Received usual care regular scheduled outpatient clinic visits. • Intervention: Goal of Care (GOC) communication intervention consisted of phone-based, pre-visit coaching about HF therapies and advance directive completion, delivered by a nurse. Patients and clinicians received a one-page patient summary outline from pre-visit coaching. • Outcomes: Patient satisfaction, symptoms of depression and anxiety, advance directive completion.	2 weeks

COPD = chronic obstructive pulmonary disease; ESRD = end-stage renal disease; RCT = randomized controlled trial; SPIRIT = Sharing Patients' Illness Representation to Increase Trust.

Table 10. Outcomes reported in the studies assessing effectiveness of shared decision-making tools

Number of Studies	Satisfaction	Symptoms of Depression	Symptoms of Anxiety	Concordance Between Patient Preferences and Care Received	Advance Directive Documentation	Dropouts Related to the Intervention
6	Patient - 4 Caregiver - 1	2	2	2	2	0

Table 11. Summary of effectiveness findings for shared decision-making tools by outcome

Type	Outcome	Comparison	Number of Studies (N Analyzed)	Findings	Strength of Evidence
Patient-centered outcomes	Patient satisfaction[45, 46, 49, 85]	Shared decision-making tools vs. control	4 RCTs (780 participants)	Shared decision-making tools may be effective for improving patient satisfaction with communication compared with usual care.	Low
	Patient symptoms of depression[45, 85]	Shared decision-making tools vs. control	2 RCTs (342 participants)	We were unable to draw conclusions.	Insufficient
	Patient symptoms of anxiety[45, 85]	Shared decision-making tools vs. control	2 RCTs (407 participants)	We were unable to draw conclusions.	Not graded
	Concordance between patient preferences and care received[45, 47]	Shared decision-making tools vs. control	2 RCTs (387 participants)	It is not clear whether the reported differences are meaningful. Shared decision-making tools may be moreeffective for increasing concordance between patient preferences and care received than usual care,	Not graded
Caregiver-centered outcomes	Caregiver satisfaction[49]	Shared decision-making tools vs. control	1 RCT (54 participants)	We were unable to draw conclusions.	Insufficient

Type	Outcome	Comparison	Number of Studies (N Analyzed)	Findings	Strength of Evidence
Healthcare utilization	Advance directives documentation[45, 48, 85]	Shared decision-making tools vs. printed materials	1 RCT (203 participants) (3 arms)	Advance care planning shared decision-making tools through peer mentoring were more effective than printed materials for increasing advance directives documentation.	Low
		Shared decision-making tools vs. control	3 RCTs (820 participants)	Advance care planning shared decision-making tools were more effective than usual care for advance directives documentation (including goals of care documentation).	Low

RCT = randomized control trial

Patient- and Caregiver-Centered Outcomes

Patient Satisfaction

We identified four RCTs of shared decision-making tools that evaluated patient satisfaction, measured as quality of patient-clinician communication (Table 11).[45, 46, 49, 85] Two studies evaluated different versions of a patient and clinician feedback intervention to enhance communication in goals of care conversations between clinicians and patients in either COPD[46] or mixed serious illness populations.[45] Two studies used a trained nurse interventionist to enhance communication between patients, caregivers, and clinicians. In one of those studies, a nurse provided education to ESRD patients and caregivers about end-of-life care[49], and in the other study a nurse provided HF patients and clinicians with a summary outline of the pre-visit engagement.[85] All studies used versions of the Quality of Communication (QOC) questionnaire; three used a version focusing on end-of-life care.[45, 49, 85]

Of the two feedback trials to enhance communication in goals-of-care conversations, one study (n=376) reported a between-group difference in improvement in the intervention group compared with usual care of 5.7 points, using the QOC questionnaire (100-point scale), (confidence interval [CI] not reported; p=0.03; Cohen effect size, 0.21).[46] Final results for the other trial (n=268) reported mean values in the intervention and control groups, respectively, of 4.6 and 2.1 points (CI and total score for the scale not reported, p=0.01).[45] One trial using a trained nurse interventionist to enhance communication about end-of life care did not report baseline results but did report results at the end of the study in the intervention group mean (standard deviation [SD]), 11.30 (1.41) and control group 7.52 (3.66), using the QOC questionnaire (4- to 12-point scale, no statistics reported) (n=56).[49] The second RCT evaluated the quality of end-of-life communication using the QOC questionnaire (4- to 12-point scale). The trial, using a nurse interventionist, evaluated quality of end-of-life communication in the intervention group 5.76 (3.18) compared with the usual care group 4.47 (2.78) (p=0.03).[85] We were unable to conduct a meta-analysis owing to incomplete reporting of results and

heterogeneity of interventions. We could not determine if these differences were clinically meaningful. Given the consistent but relatively small differences, we concluded that advance care planning shared decision-making tools may be effective for improving patient satisfaction with communication compared with usual care (SOE: Low).

Caregiver Satisfaction

The RCT (n=54) that used a trained nurse interventionist to enhance communication between ESRD patients and caregivers about end-of-life care also evaluated caregiver satisfaction using the QOC questionnaire (4- to 12-point scale).[49] The study did not report baseline results but reported results at the end of the study for the intervention group mean (SD) 11.58 (0.72) and control group 10.22 (2.49). Given that there was only one small study with moderate risk of bias, we were unable to draw a conclusion (SOE: Insufficient).

Symptoms of Depression

Two RCTs of a patient and clinician feedback intervention to enhance communication in goals-of-care conversations between clinicians and patients reported symptoms of depression using the Patient Health Questionnaire (PHQ) scale.[45, 85] One study using the PHQ-8 scale reported results at the end of the study: 4.84 (95% CI, 4.17 to 5.51) in the control group compared with 5.93 (95% CI, 5.05 to 6.81) in the intervention group (p=0.34).[45] The second study, using the PHQ-9 scale, found no change in symptoms of depression in the control group (mean (SD) 5.60 (5.80)) or the intervention group (5.47 (5.03)).[85] Although there were statistically significant between-group differences for depression in the one small study that reported change with the intervention, the differences were too small to be clinically meaningful. Given imprecise and incomplete reporting of results, we are unable to draw conclusions (SOE: Insufficient).

Symptoms of Anxiety

Two RCTs of a patient and clinician feedback intervention to enhance communication in goals-of-care conversations between clinicians and patients reported symptoms of anxiety using the Generalized Anxiety Disorder-7 scale.[45, 85] One study reported followup results, only, with 3.08 (95% CI, 2.44 to 3.72) in the control group compared with 3.38 (95% CI, 2.67 to 4.08) in the intervention group (p=0.85).[45]. One study found no increase in anxiety using the Generalized Anxiety Disorder scale, post intervention, reporting a mean of 4.15 (4.70) in the control group, and in the intervention group of 3.72 (5.48), p=0.09.[85] This difference was not clinically meaningful. Given imprecise and incomplete reporting of results, we were unable to draw conclusions.

Concordance Between Patient Preferences and Care Received

Two RCTs examined concordance between patient preferences and care received.[45, 47] One study evaluated an intervention to enhance communication in goals-of-care conversations between clinicians and patients,[45] and one study used a 1 to 1.5-hour interview intervention conducted by a trained facilitator.[47] One of these studies, using post-death data for patient participants with a low chance of survival, found receipt of care concordant with initial choices for 46 of the 62 intervention patients (74%) and for 30 of 48 control patients (62%) (no statistics reported).[47] For the other study, patient-reported goal-concordant care was 70 percent in the intervention group compared with 57 percent in the control group (p=0.08).[45] Shared decision-

making tools may improve concordance between patient preferences and care received, but it is not clear if the reported differences are meaningful.

Healthcare Utilization

Advance Directives Documentation

Three RCTs evaluated the impact of interventions on advance directive or goals-of-care documentation (total n=775). One study evaluated an intervention to enhance communication in goals-of-care conversations between clinicians and patients.[45] In this study, documentation of goals-of-care conversations occurred in 62 percent of the intervention group compared with 17 percent in the control group ($p<0.001$). One study included two intervention arms for advance directives, one arm using a peer mentoring intervention and one arm using printed material.[48] In the arm using peer mentoring, completion of the advance directive was 35 percent (22/63) in the intervention group compared with 12 percent (7/59) in the arm using printed material (odds ratio [OR] 0.25; $p<0.05$) and 10 percent (8/81) in the control group (OR 0.20, $p<0.01$).[48] One smaller study did not find a statistically significant difference between the intervention group 16 percent (7/41) and control group 7.7 percent (3/39) in the completion of advance directives ($p=0.24$).[85] In three studies, the increases in documentation were consistent and suggest that shared decision-making tools were more effective than usual care for increasing advance directive documentation. (SOE: Low).

Adverse Effects

Dropouts Related to the Intervention

No RCTs reported dropouts related to the intervention.

Key Question 4b. What is the effectiveness of palliative care training and educational materials (with or without other intervention components) for nonpalliative care clinicians caring for patients with serious life-threatening chronic illness or conditions in ambulatory settings?

We identified no studies for this Key Question.

Key Question 5b. What is the effectiveness of models and multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings?

Key Points

- Models for integrating palliative were not more effective than usual care for improving patient health-related quality of life (HRQOL) (SOE: Moderate).
- Models for integrating palliative care may have little to no effect compared with usual care for reducing overall symptom burden (SOE: Low) and were not more effective than usual care for improving depressive symptom scores (SOE: Moderate).
- Models for integrating palliative care may have little to no effect compared with usual care on increasing patient satisfaction (SOE: Low), and no studies addressed caregiver satisfaction.
- Models for integrating palliative care were more effective than usual care for increasing advance directive documentation (SOE: Moderate).
- Multimodal interventions may have little to no effect on increasing advance directive documentation (SOE: Low), and no studies addressed the effect of multimodal interventions for other critical (graded) outcomes.

Description of Included Studies

We identified 17 articles describing 14 studies assessing the effectiveness of models for integrating palliative care or multimodal interventions for integrating palliative care in ambulatory settings.[24-26, 67-79, 86] Multimodal interventions, for the purposes of this review, are defined as combinations of the different types of included specific interventions: identification of patients, education for patients and caregivers, shared decision-making tools, and education for nonpalliative care clinicians. These 14 studies included 2,934 patients and 501 caregivers. Nine studies were RCTs and five were controlled (nonrandomized) trials or prospective cohorts. One controlled trial (CT) and one RCT evaluated the effect of multimodal interventions that included a trigger plus clinician training/education. Of the twelve trials assessing models for integrating palliative care, four were shared care models, four involved care coordinators or social workers in care delivery, and four used a consultative model. Followup ranged from 2 weeks to 2 years.

Seven studies were multicenter [Tables 12-17, see Results Appendix D (evidence tables) for full study characteristics].

Table 12. Characteristics of effectiveness studies assessing models for integrating palliative care

Type	Author, Year	Study Characteristics	Intervention Description	Followup Duration
Shared Care Models	Kluger, 2020[67]	n=210 patients and n=175 caregivers • RCT, multi-center, academic • Patients with Parkinson's disease and related disorders with moderate to high palliative care needs and their caregivers • Nonprofit funding	• Control: Neurologist and primary care practitioner provided standard care. • Intervention: Standard care plus outpatient integrated palliative care delivered by a neurologist, social worker, chaplain, nurse, and palliative medicine specialist. Palliative visits were every 3 months in-person or by telemedicine with as-needed followup phone calls. • Model type: Shared care.	12 months
	Owens, 2013[68]	n=49 • Prospective cohort study, single center, academic • Integrated primary and palliative care clinic, patients with life-limiting illness • Funding source not reported	• Control: Usual care (not described). • Intervention: Primary Palliative Care Clinic: Integrated model of primary and palliative care led by nurse practitioner where consistent care was delivered by primary or palliative care clinician. • Model type: Shared care.	Varied, 2 weeks to 9 months
	Rogers, 2017[69]	n=150 • RCT, single center, academic • Patients with advanced heart failure and high six-month mortality risk based on covariates measured at baseline • Government funding	• Control: Cardiology-directed team with focus on symptom relief and evidence-based therapies based on current guidelines. • Intervention: Palliative Care in Heart Failure: Usual care combined with an integrated care model of palliative care nurse practitioner supported by a palliative care physician managing physical symptoms, psychosocial and spiritual concerns, and advance care planning. • Model type: Shared care.	6 months

Type	Author, Year	Study Characteristics	Intervention Description	Followup Duration
	O'Riordan, 2019[70]	n=39 • RCT, single-center, academic • Patients with heart failure primary diagnosis or symptomatic heart failure as defined by New York Heart Association Class II-IV in current hospitalization or within prior 6 months • Nonprofit funding	• Control: Standard care was guideline-driven heart failure treatment. • Intervention: Intensive palliative care delivered by an interdisciplinary care team consisting of a nurse practitioner, physician, social worker, and chaplain. Consultation included prescribing medication, advance care planning, documentation completion, and provided needed psychosocial and spiritual support. First consultation occurred during the hospitalization with one-week in-person followup assessment combined with five monthly consultants (at least 2 in person or by teleconference. Model type: Shared care.	6 months
Consultative Care Models	Bekelman, 2015[72]	n=392 • RCT, multi-center, Veterans Affairs • Primary care, patients with heart failure • Government funding	• Control: Continual care from primary care clinician and regular telehealth nurses if patient had previously enrolled, given information sheet during enrollment on self-management of heart failure, depression diagnosis provided to primary care clinician. • Intervention: Patient-Centered Disease Management (PCDM): heart failure disease management, home telemonitoring with patient self-support, and screening and management of depression. Collaborative care team consisted of a nurse coordinator (registered nurse), a primary care physician, a cardiologist, and a psychiatrist. • Model type: Consultative care.	12 months

Type	Author, Year	Study Characteristics	Intervention Description	Followup Duration
	Bekelman, 2018[71]	n=314 • RCT, multi-center, academic and Veterans Affairs health systems • Primary site not reported, patients with heart failure and reduced health status • Government funding	• Control: As needed, unstructured symptoms assessment and management by primary care physician or nurse practitioner; referral to social worker for psychosocial assessment and management, as needed; information sheets on self-care for heart failure. • Collaborative Care to Alleviate Symptom and Adjust to Illness (CASA): Clinician training/education combined with a palliative care model. Routine, structured symptom assessment and management by nurse (6 sessions, 1 to 2/month), routine, structured psychosocial assessment and management by social worker via telephone (6 sessions), collaborative care team including palliative care specialist and cardiologist provided care review and supervision. Nurse was trained in assisting with communication (1 hour), motivational interview (4 hours), and guidelines on symptoms (3 hours); social worker received training on psychosocial intervention training and supervision on followup visits (8 hours). • Model type: Consultative care.	6 months
	Feely, 2016[73]	n=92 • Prospective cohort study, single center, academic • Outpatient hemodialysis unit, adult patients receiving hemodialysis • Funding source not reported	• Control: Usual care (not described). • Intervention: Integrated model of palliative care physician. consultations on a hemodialysis unit • Model type: Consultative care.	6 months
	Rabow, 2004[74, 75]	n=90 • Controlled trial, single center, academic • Outpatient general medicine clinic, patients diagnosed with cancer, advanced COPD, or advanced CHF with life expectancy of 1 to 5 years but not ready for hospice • Non-profit funding	• Control: Usual primary care (not described). • Intervention: Comprehensive Care Team (CCT) patient/caregiver education combined with an integrated model of a social worker, nurse, chaplain, pharmacist, psychologist, art therapist, volunteer coordinator and three physicians addressing physical, emotional, and spiritual issues. • Model type: Consultative care.	12 months

Type	Author, Year	Study Characteristics	Intervention Description	Followup Duration
Involving Care Coordinators/Social Workers In Care Delivery	Engelhardt, 2006[76]	n=275 patients and n=168 caregivers • RCT, multi-center, Veterans Affairs (not specified if academic) • Patients with COPD or CHF who have one or more admissions to an intensive-care unit or two or more acute-admissions in the last 6 months • Non-profit funding	• Control: Usual care (not described). • Intervention: Advanced Illness Coordinated Care Program (AICCP): Six-session in-person intervention delivered by care coordinators (e.g., nurses, social workers – not specified) in the practices focused on helping patients develop questions and providing information to physicians, health literacy, care coordination, psychosocial issues, self-management, and end-of-life planning. • Model type: Involving Care Coordinators/Social Workers In Care Delivery.	6 months
	O'Donnell, 2018[78]	n=50 • RCT, single-center, academic • Patients with heart failure who had recent hospitalization and are at high risk for poor prognosis • Private foundation funding	• Control: Usual care on advanced care planning and HRQOL. • Social worker-led palliative care intervention: Palliative care model integrating social worker into practice, guided by Serious Illness Conversation Guide, social worker led participants through structured goals-of-care discussion initially at the inpatient setting with subsequent telephone or clinic-based followup. • Model type: Involving Care Coordinators/Social Workers In Care Delivery.	6 months
	Engelhardt, 2009[77]	n=532 • Controlled trial, multi-center, integrated managed care • Kaiser Permanente health system, patients with advanced stages of cancer, congestive heart filature, end-stage pulmonary disease, and end-stage renal disease and their caregivers • Nonprofit and Kaiser Permanente funding	• Control: Usual care (not described). • Intervention: Advanced Illness Coordinated Care Program (AICCP): Integrated model with six-session intervention delivered by social workers or health educators focused on nondirective health counseling, education, and care coordination in patients with advanced illness. • Model type: Involving Care Coordinators/Social Workers In Care Delivery.	Varied, 4 to 9 months

Type	Author, Year	Study Characteristics	Intervention Description	Followup Duration
	Dionne-Odom, 2020[79]	n=158 caregivers • RCT, multi-center, academic • Caregivers of patients with New York Heart Association Class III or IV heart failure and/or AHA/ACC stage C/D heart failure • Government funding	• Control: No intervention. • Intervention: Four weekly psychosocial and problem-solving support telephonic sessions lasting between 20 and 60 minutes facilitated by a trained nurse coach plus monthly followup. • Model type: Involving Care Coordinators/Social Workers In Care Delivery.	16 weeks

COPD = chronic obstructive pulmonary disease; CHF = congestive heart failure; CCT = comprehensive care team; AAICP = advanced illness coordinated care program; PCDM = patient-centered disease management; CASA = collaborative care to alleviate symptoms and adjust to illness; RCT = randomized controlled trial; HRQL= health-related quality of life; AHA= American Heart Association; ACC= American College of Cardiology.

Table 13. Characteristics of effectiveness studies assessing multimodal interventions

Author, Year	Study Characteristics	Intervention Description	Followup Duration
Lakin, 2017[24, 25, 86]	n=178 • Controlled trial, single-center, academic • Primary care clinics, patients with all serious illnesses enrolled based on comorbidity and utilization and validation by patient's primary care physician • Nonprofit and industry funding	• Control: Usual care (not described). • Serious Illness Program: Multimodal clinician training/education combined with triggers. Coaching model of structured teaching by palliative care experts, including demonstration and practice with trained medical actors followed by monthly calls and, as requested, by phone, email, or in person for intervention clinicians. Trigger via coaching of Surprise Question was initiated with intervention clinicians. • Multimodal intervention: Clinician training/education plus trigger.	32 months
Goldstein, 2019[26]	n=563 • RCT, multi-center, academic • Advanced heart failure practices, patients with advanced heart failure with implantable cardioverter-defibrillators (ICDs) with greater than two heart-failure-related hospitalizations in the last year • No funding reported	• Control: No clinician training was provided but had discussions regarding deactivation. • Intervention: Multimodal clinician training/education combined with automatic triggers to initiate ICD deactivation discussion. Interactive 90-minute clinician communication training on advance care planning with focus on ICD deactivation and goals of care and automated electronic reminders to clinicians. • Multimodal intervention: Clinician training/education plus trigger	24 months

RCT = randomized controlled trial; ICD-10 = International Classification of Diseases, Tenth Revision.

Table 14. Patient outcomes reported in the effectiveness studies assessing models for integrating palliative care and multimodal interventions

Intervention Type	Number of Studies	Satisfaction	HRQOL	Overall Symptom Burden	Symptoms of Depression	Symptoms of Anxiety	Psychological Well-Being	Pain	Dyspnea	Fatigue
Multimodal Interventions	2	0	0	0	0	0	0	0	0	0
Models for Integrating Palliative Care	11	3	8	2	9	8	5	5	5	3

HRQOL = health-related quality of life.

Table 15. Caregiver outcomes reported in the effectiveness studies assessing models for integrating palliative care and multimodal interventions

Intervention Type	Number of Studies	Satisfaction	HRQOL	Symptoms of Depression	Symptoms of Anxiety	Psychological Well-Being	Burden, Impact or Strain
Multimodal Interventions	0	0	0	0	0	0	0
Models for Integrating Palliative Care	2	0	1	2	2	1	2

Table 16. Health utilization outcomes reported in the effectiveness studies assessing models for integrating palliative care and multimodal interventions

Intervention Type	Number of Studies	Concordance	Use and Length of Hospice Care	Hospitalizations	AD Documentation	Cost and Resource Use	Dropouts Related to the Intervention
Multimodal Interventions	2	0	1	1	1	1	0

Intervention Type	Number of Studies	Concordance	Use and Length of Hospice Care	Hospitalizations	AD Documentation	Cost and Resource Use	Dropouts Related to the Intervention
Models for Integrating Palliative Care	11	1	0	4	7	4	0

AD = advance directive.

Table 17. Summary of effectiveness findings for models for integrating palliative care and multimodal interventions by outcome

Type	Outcome	Comparison	Number of Studies (N at Analysis)	Findings	Strength of Evidence
Patient-centered outcomes	Patient satisfaction [70, 74-76]	Models for integrating palliative care vs. usual care	2 RCTs (n=216) 1 CT (n=90)	Models for integrating palliative care may have little to no effect on patient satisfaction compared with usual care.	Low
	Patient HRQOL [67, 69-72, 74, 75, 77, 78]	Models for integrating palliative care vs. usual care	6 RCTs (n=897) 2 CTs (n=90+)	Results were consistently not statistically or clinically different between groups. Models for integrating palliative care were not more effective than usual care for HRQOL.	Moderate
	Overall symptom burden [67, 71]	Models for integrating palliative care vs usual care	2 RCTs (n=419)	Models for integrating palliative care may have little to no effect on overall symptom burden compared with usual care.	Low
	Patient symptoms of depression [67-75, 78]	Models for integrating palliative care vs. usual care	6 RCTs (n=553+) 1 CT (n=90) 2 prospective cohort studies (n=86)	In a pooled analysis of three RCTs [67, 70, 78], we found no difference in symptoms of depression with a model for integrating palliative care compared with usual care (calculated standardized mean difference, -0.09; 95% CI, -0.35 to 0.17). Models for integrating palliative care were not more effective than usual care for symptoms of depression.	Moderate

Type	Outcome	Comparison	Number of Studies (N at Analysis)	Findings	Strength of Evidence
	Patient symptoms of anxiety[67-71, 73-75, 78]	Models for integrating palliative care vs. usual care	5 RCTs (n=561) 1 CT (n=90) 2 prospective cohort studies (n=87)	In a pooled analysis of three RCTs [67, 70, 78], we found no differences in anxiety for patients enrolled in a model for integrating palliative care compared with usual care (calculated standardized mean difference, 0.06; 95% CI, -0.2 to 0.32, I-squared=0%}. No statistically or clinically significant between-group differences. Models for integrating palliative care were not more effective than usual care for symptoms of anxiety.	Not graded
	Patient psychological well-being[67, 69, 74, 75, 77, 78]	Models for integrating palliative care vs. usual care	3 RCTs (n=281) 2 CTs (n=90+)	Meta-analysis of the three RCTs showed no difference in psychological well-being compared with usual care (calculated standardized mean difference, 0.01; 95% CI, -0.39 to 0.41). Models for integrating palliative care were not more effective than usual care for symptoms of anxiety.	Not graded
	Pain[68, 70, 71, 73-75]	Models for integrating palliative care vs. usual care	2 RCTs (n=277) 1 CT (n=90) 2 prospective cohort studies (n=102)	None of the differences were clinically meaningful. Models for integrating palliative care were not more effective than usual care for pain.	Not graded
	Dyspnea[68, 70, 71, 73-75]	Models for integrating palliative care vs. usual care	2 RCTs (n=278) 1 CT (n=90) 2 prospective cohort studies (n=88)	Results were not clinically meaningful. Models for integrating palliative care were not more effective than usual care for dyspnea.	Not graded
	Fatigue[68, 71, 73]	Models for integrating palliative care vs. usual care	1 RCT (n=248) 2 prospective cohort studies (n=88)	Primarily based on the larger RCT results, models for integrating palliative care may not be more effective than usual care for fatigue.	Not graded
	Concordance between patient preferences and care received[78]	Models for integrating palliative care vs. usual care	1 RCT (n=31)	We were unable to draw conclusions.	Not graded

Type	Outcome	Comparison	Number of Studies (N at Analysis)	Findings	Strength of Evidence
Caregiver-centered outcomes	Caregiver HRQOL[79]	Models for integrating palliative care vs. usual care	1 RCT (n=82)	Models for integrating palliative care and usual care may have little to no effect on caregiver HRQOL compared with usual care.	Not graded
	Caregiver symptoms of depression[67, 79]	Models for integrating palliative care vs. usual care	2 RCTs (n=228)	Differences were not clinically meaningful. Models for integrating palliative care were not more effective than usual care for symptoms of depression.	Not graded
	Caregiver symptoms of anxiety[67, 79]	Models for integrating palliative care vs. usual care	2 RCTs (n=228)	Differences were not clinically meaningful. Models for integrating palliative care were not more effective than usual care for symptoms of anxiety.	Not graded
	Caregiver psychological well-being[67]	Models for integrating palliative care vs. usual care	1 RCT (n=147)	There may be little to no difference in caregiver psychological well-being between models and usual care.	Not graded
	Caregiver burden, impact, or strain[67, 79]	Models for integrating palliative care vs. usual care	2 RCTs (n=229)	There may be little to no difference in caregiver burden, impact, or strain between models and usual care.	Not graded
Healthcare utilization	Use and length of hospice care[24, 25]	Multimodal interventions vs. usual care	1 CT (n=74)	We were unable to draw conclusions.	Not graded
	Hospitalizations[26, 71, 72, 74, 75, 77]	Multimodal interventions vs. usual care Models for integrating palliative care vs. usual care	1 RCT (n=525) 2 RCT (n=698) 2 CT (n=493)	Multimodal: Results of one large RCT suggest that multimodal interventions may have little to no effect on hospitalizations compared with usual care. Models: Models for integrating palliative care were not more effective than usual care for hospitalizations.	Not graded

Type	Outcome	Comparison	Number of Studies (N at Analysis)	Findings	Strength of Evidence
	Advance directive documentation[26, 67, 70, 73-78]	Multimodal interventions vs. usual care Models for integrating palliative care vs. usual care	1 RCT (n=167) 4 RCTs (n=424) 2 CT (n=450) 1 prospective cohort studies (n=92)	Multimodal: Multimodal interventions may have little to no effect on advance directive documentation. Models: In a pooled analysis of four RCTs [67, 70, 76, 78], we found that patients enrolled in models integrating palliative care were 62.0% more likely to have a higher completion of AD documentation at 6 months (relative risk, 1.620; CI, 1.350 to 1.945) Based on the results of the meta-analysis and consistent results from additional studies, models for integrating palliative care are more effective than usual care for advance directive documentation.	Low Moderate
	Cost and resource use[68, 74-77, 86]	Multimodal interventions vs. usual care Models for integrating palliative care vs. usual care	1 CT (n=124) 3 CT (n=768) 1 prospective cohort study (n=49)	Multimodal: Based on results of one CT, multimodal interventions may have little to no effect on cost and resource use compared with usual care. Models: Studies varied widely in reporting and results, so we were unable to draw conclusions.	Not graded Not graded

RCT = randomized controlled trial; CT = controlled trial; HRQOL = healthrelated quality of life,;CI = confidence interval

Patient-Reported Outcomes

Satisfaction

Models for Integrating Palliative Care

Two RCTs and one CT, reported in four articles, assessed the effect of models for integrating palliative care on patient satisfaction.[70, 74-76]

In the first RCT, patient satisfaction was assessed using an investigator-constructed 5-point Likert-type scale. Patients in the intervention group reported higher post-test satisfaction mean scores compared with those in the control group [control 3.98 (0.67), intervention 4.07 (0.68),

p=0.03].[76] It is not clear whether this is a meaningful difference. In the second RCT, patient satisfaction was assessed with an unnamed scale.[70] There were no reported differences in satisfaction between groups at 6 months.

Assessing satisfaction using the Group Health Association of America Consumer Satisfaction Survey (score ranges from 20 to 100), the CT reported that the control group had a total satisfaction score of 72.4 compared with 70.1 in the intervention arm (p=0.26).[74, 75]

Models may have little to no effect on improving compared to usual care (SOE: Low).

Multimodal Interventions

No studies evaluating multimodal interventions assessed patient satisfaction.

Health-Related Quality of Life

Models for Integrating Palliative Care

Six RCTs and two CTs, reported in nine articles, assessed the effect of models for integrating palliative care on HRQOL.[67, 69-72, 74, 75, 77, 78]

Four of the RCTs assessed HRQOL with the Kansas City Cardiomyopathy Questionnaire (KCCQ), which is a 0- to 100-point scale, where a change of 5 points is potentially clinically meaningful. One used the Minnesota Living with HF Questionnaire (MLHFQ) (0- to 105-point scale) and another the Quality of Life in Alzheimer's Disease scale (QOL-AD) (13- to 52-point scale). Two RCTs also used the Functional Assessment of Chronic Illness Therapy – Palliative Care scale (FACIT-PAL) (0- to 184-point scale).

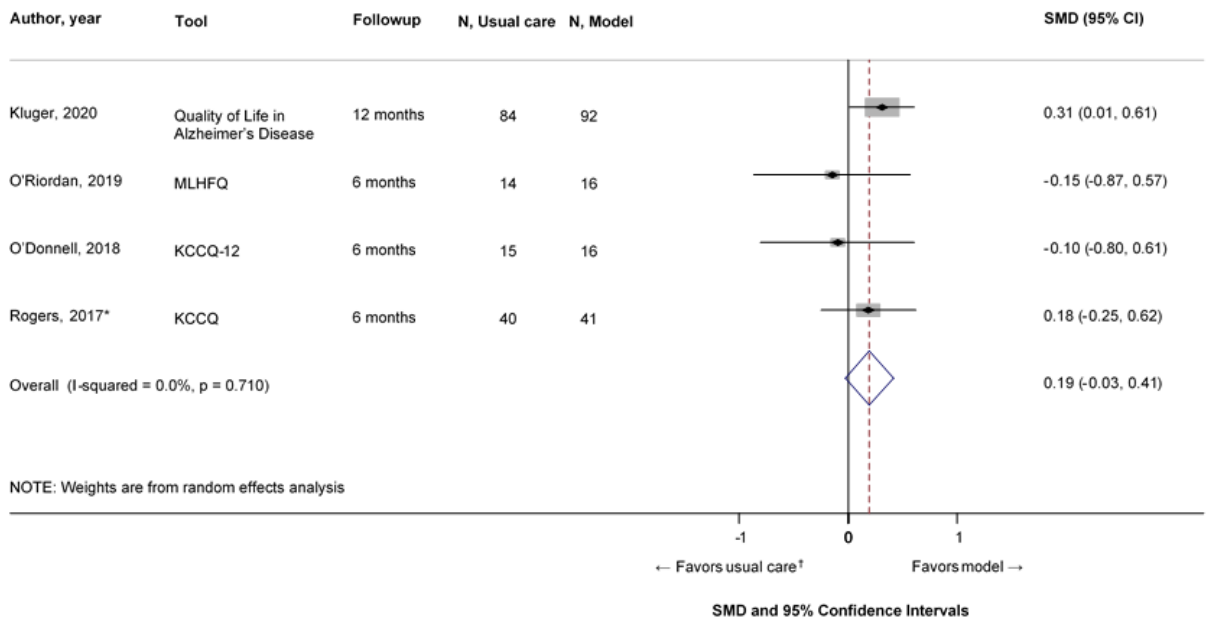
In a meta-analysis of 4 RCTs,[67, 69, 70, 78] we found no difference in HRQOL in patients enrolled in a model for integrating palliative care compared with usual care (calculated standardized mean difference, 0.19; 95% CI, -0.03 to 0.41, I-squared=0.0%) (Figure 2, see also Appendix D for more detailed forest plot of HRQOL).

The two additional RCTs did not report either followup data or variability measurements, so we were unable to calculate a mean between-group difference. Each of these reported no clinically meaningful differences between groups, consistent with our meta-analysis. The first RCT reported a difference in the KCCQ of 2.6 (95% CI, -1.3 to 6.6) between groups at 6 months (p=0.19).[71] The second RCT reported that, at 1 year, KCCQ scores had increased by 13.5 for both the control and intervention groups (p=0.97).[72]

The results from the two CTs are also consistent with our meta-analysis results. In the first CT, at 12 months, the control group reported a total mean score on the Multidimensional Quality of Life Scale – Cancer version (0- to 100-point scale) of 67.7 compared with the intervention group mean score of 69.3 (p=0.43).[74] No variability was reported, so we were unable to calculate a mean between-group difference. The second CT assessed HRQOL with the McGill Quality of Life Questionnaire [usual care, mean (SD) 4.89 (1.14) and intervention, mean (SD) 5.03 (0.87), p>0.05].

Across different scales, the results reported from the meta-analysis and individual studies were consistently not statistically or clinically meaningful. Models for integrating palliative care did not improve HRQOL (SOE: Moderate).

Figure 2. Meta-analysis of the effects of models for integrating palliative care on improving health-related quality of life in patients with noncancer serious chronic illness compared with usual care



CI=confidence interval; KCCQ-12=Kansas City Cardiomyopathy Questionnaire-12 item; MLHFQ=Minnesota Living with Heart Failure Questionnaire; N=sample size; SMD=standardized mean difference; KCCQ=Kansas City Cardiomyopathy Questionnaire

*Rogers, 2017 et al.[69] standardized mean difference calculated using difference between baseline and outcome at 6 months.
†A higher standardized mean difference for quality of life outcomes favors the intervention model over usual care.

Multimodal Interventions

No studies evaluating multimodal interventions assessed HRQOL.

Overall Symptom Burden

Models for Integrating Palliative Care

Two RCTs assessed the effect of models for integrating palliative care on overall symptom burden[67, 71]. One study assessed the effect of a shared care model on heart failure patients over a period of 6 months. Symptom burden was described using the General Symptom Distress Scale (GSDS) (0- to 10-point scale)[71]. At 6 months, the reported mean between-group difference was 0.1 (95% CI, -0.5 to 0.7, p=0.8).

The second RCT assessed the effect of a model on patients with Parkinson's disease and related disorders over a period of 12 months. Symptom burden was assessed using the Edmonton Symptom Assessment Scale – Parkinson's Disease (ESAS-PD) overall score (0- to 140-point scale). At 12 months, the reported mean between group difference was –8.27 (95% CI, -13.9 to –2.6, p=0.004).

Given inconsistent results that are likely not clinically meaningful, models for integrating palliative care may have little to no effect compared with usual care for overall symptom burden (SOE: Low).

Multimodal Interventions

No studies evaluating multimodal interventions assessed overall symptom burden.

Symptoms of Depression

Models for Integrating Palliative Care

Six RCTs, one CT and two prospective cohort studies, reported in ten articles, assessed the effect of models for integrating palliative care on depression.[67-75, 78] Depression was assessed using a wide variety of scales.

In a meta-analysis of three RCTs,[67, 70, 78] we found no difference in symptoms of depression in patients enrolled in a model for integrating palliative care compared with usual care (calculated standardized mean difference, -0.09; 95% CI, -0.35 to 0.17, I-squared=0.0%) (Figure 3).

Three RCTs, one CT and two prospective cohort studies could not be included in the meta-analysis owing to missing baseline and/or variability data. Two of these RCTs assessed depression with the Patient Health Questionnaire-9 (PHQ9) (0- to 27-point range). The first RCT reported a difference of -1.4 (95% CI, -2.6 to -0.2) between groups (p=0.02).[71] The other RCT reported a difference of 2.1 (95% CI, 0.43 to 3.78) between groups (p=0.01).[72] Although these results were statistically significantly different, neither was clinically meaningful.

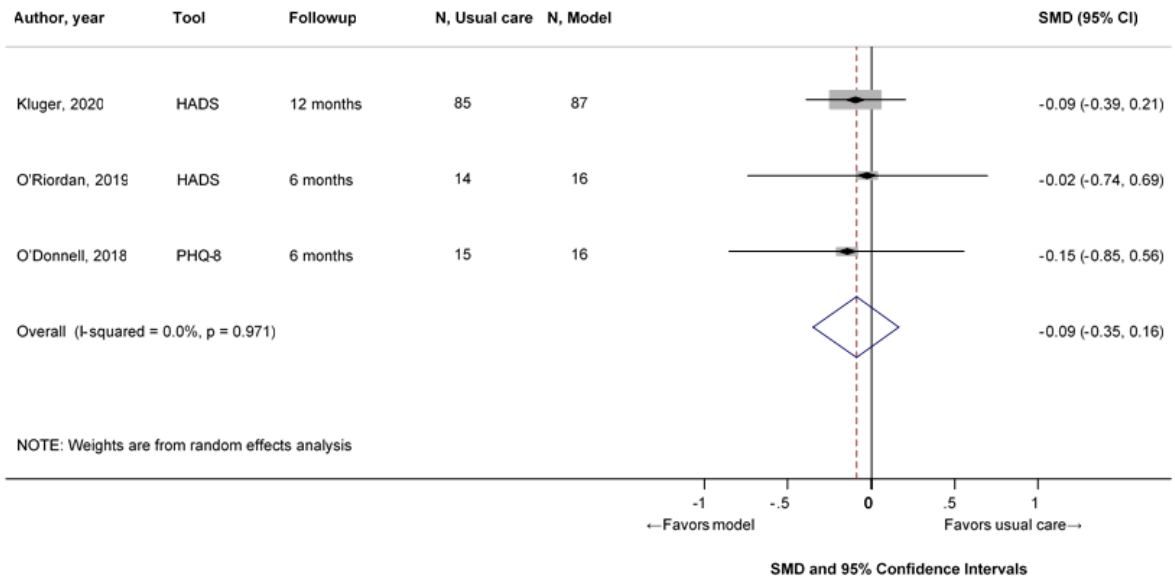
The third RCT assessed the impact of a shared care model on depression using the Hospital Anxiety and Depression Scale (HADS) (0- to 21-point scale) and reported a difference of -1.94 (95% CI, 3.57 to -0.31) between groups (p=0.02) that was clinically significant.[69]

The two prospective cohort studies assessed depression with the Edmonton Symptom Assessment Scale (ESAS) (a 10-point scale). One cohort reported a change from a mean of 0.96 +/- 1.99 at baseline to 0.87 +/- 2.29 (p=0.7) at 6 months.[73] The other cohort reported a mean change (SD) of 2.65 (3.19) to 2.7 (2.74) (no statistics reported).[68] Neither result was clinically meaningful.

The CT evaluated the impact of a shared care model on depressive symptoms with the Center for Epidemiological Studies Depression Scale (0- to 60-point scale). At 12 months, the control group reported a score of 15.3 compared with 12.4 in the intervention arm (p=0.28).[74, 75]

Given consistent results with the meta-analysis and additional studies, models for integrating palliative care were not more effective than usual care for depressive symptom scores (SOE: Moderate).

Figure 3. Meta-analysis of the effects of models for integrating palliative care on improving depressive symptom scores in patients with noncancer serious chronic illness compared with usual care



CI=confidence interval; HADS= Hospital Anxiety and Depression Scale; N=sample size; PHQ-8=Patient Health Questionnaire depression scale-eight item; SMD=standardized mean difference

Multimodal Interventions

No studies evaluating multimodal interventions assessed symptoms of depression.

Anxiety Symptom Scores

Models for Integrating Palliative Care

Five RCTs, one CT and two prospective cohort studies assessed the effect of models for integrating palliative care on anxiety.[67-71, 73-75, 78]

Four RCTs assessed the impact of models for integrating palliative care on heart failure patients over a period of 6 months, and the fifth evaluated the impact of integrating palliative care on patients with Parkinson's disease and related disorders, also over a period of 6 months. In a meta-analysis of three RCTs,[67, 70, 78] we found no difference in anxiety symptoms for patients enrolled in a model for integrating palliative care compared with usual care (calculated standardized mean difference, 0.06; 95% CI, -0.2 to 0.32, I-squared=0%) (Appendix D).

Two RCTs, one CT, and two prospective cohort studies could not be included in the meta-analysis owing to missing baseline and/or variability data. The first RCT assessed the impact of a consultative care model on anxiety using the Generalized Anxiety Disorder-7 (GAD-7) scale (0- to 21-point scale) and reported a difference of -0.9 (95% CI, -2 to 0.13) between groups at 6 months (p=0.09) that was not clinically meaningful.[71] The second RCT assessed the impact of a shared care model on anxiety using the HADS and reported a difference of -1.83 (95% CI, -3.46 to -0.02) between groups at 6 months (p=0.048) that was clinically significant.[69]

Both prospective cohort studies assessed anxiety with the ESAS (a 10-point scale). In one cohort, anxiety changed from a mean of 0.98 +/- 1.82 at baseline to 1.08 +/- 2.86 (p=0.8).[73] In the other cohort, anxiety changed from a mean (SD) of 1.65 (2.47) to 1.94 (2.5) (no statistics reported).[68] Neither was clinically meaningful.

The CT assessed anxiety using the Profile of Mood States and reported a score of 5.9 in the control group compared with 5.3 in the intervention arm (p=0.68).[74, 75]

Any differences reported were not statistically significant or clinically meaningful, and our meta-analysis found no difference. Models for integrating palliative care were not more effective than usual care for anxiety symptom scores.

Multimodal Interventions

No studies evaluating multimodal interventions assessed anxiety symptom scores.

Psychological Well-Being

Models for Integrating Palliative Care

Three RCTs and two CTs, reported in six articles, assessed the effect of models for integrating palliative care on psychological well-being.[67, 69, 74, 75, 77, 78]

Meta-analysis of the three RCTs showed no difference in psychological well-being compared with usual care (calculated standardized mean difference, 0.01; 95% CI, -0.39 to 0.41, I-squared=55.3%) (Appendix D).[67, 69, 78]

The two CTs were not included in the analysis, because not enough information was available for calculations. Both reported results consistent with our meta-analysis. One CT assessed the impact of care coordinators on psychological well-being using the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale (0- to 48-point scale). In that CT, the control group reported a mean (SD) score of 32.05 (10.53) compared with 34.43 (9.03) in the intervention arm (p>0.05). The second CT assessed the impact of a shared care model at 12 months using the Spiritual Well Being Scale (20- to 120-point scale). Patients in the intervention group reported a score of 105.5 compared with 92.4 in the control group (p=0.007). These differences were likely not clinically meaningful.

Models for integrating palliative care were not more effective than usual care in improving psychological well-being.

Multimodal Interventions

No studies evaluating multimodal interventions assessed psychological well-being.

Pain

Models for Integrating Palliative Care

Two RCTs, one CT, and two prospective cohort studies assessed the effect of models for integrating palliative care on pain.[68, 70, 71, 73-75]

One RCT evaluated a consultative care model in patients with CHF over a period of 6 months.[71] This RCT assessed pain with a composite outcome from the Brief Pain Inventory called PEG, for pain intensity (P), interference with enjoyment of life (E), and interference with general activity (G). At 6 months, there was a difference of 0.3 [95%, CI -0.3 to 0.9; between groups (p=0.35)].

The second RCT also evaluated a model in patients with CHF over a period of 6 months. [70] This RCT assessed pain using the numeric rating scale from the Brief Pain Inventory and reported no differences between groups over the course of the study.

The CT evaluated a consultative care model including patients with COPD, CHF, and cancer and completing assessment at 12 months .[74, 75] Assessing pain using the numeric rating scale of

the Brief Pain Inventory (BPI), the control group reported an average pain rating of 4.5 compared with 3.6 in the intervention arm (p=0.41).

One prospective cohort study evaluated a consultative model on a hemodialysis unit over a period of 6 months .[73] The other study evaluated the effect of a shared care model on a wider patient population over a time period ranging from 2 weeks to 9 months.[68] Both prospective cohort studies assessed pain with the ESAS (a 10-point scale). In one cohort study, pain changed from a mean of 1.34 +/- 2.39 at baseline to 2.04 +/- 2.47 (p=0.04).[73] In the other cohort study, pain changed from a mean (SD) of 3.59 (3.11) to 3.74 (2.57) (no statistics reported).[68]

None of the differences reported in these studies was clinically meaningful. Models for integrating palliative care were not more effective than usual care for pain.

Multimodal Interventions

No studies evaluating multimodal interventions assessed pain.

Dyspnea

Models for Integrating Palliative Care

Two RCTs, one CT, and two prospective cohort studies assessed the effect of models for integrating palliative care on dyspnea.[68, 70, 71, 73-75]

One RCT evaluated a consultative care model in patients with CHF over a period of 6 months.[71] This trial assessed dyspnea using a numeric rating scale and reported a difference of 0.1 [95% CI, -0.5 to 0.7 between groups at 6 months (p=0.76)]. The second RCT also evaluated a model in patients with CHF over a period of 6 months.[70] This RCT assessed dyspnea using the Borg rating scale and reported no differences between groups over the course of the study.

The CT evaluated a consultative care model over a period of 12 months and included patients with COPD, CHF, and cancer.[74, 75] This trial assessed dyspnea using the University of California, San Diego Shortness of Breath Questionnaire and, in contrast to the RCT, reported improvements in the intervention group. The odds of an intervention patient reporting any dyspnea were significantly less than usual care patients at 12 months (OR 6.07; 95% CI, 1.04 to 35.56). At 12 months, the degree to which dyspnea interfered (0 to 105) was reported as 40.6 in the control group compared with 25.4 in the intervention arm (p=0.01). At 12 months, the frequency at which dyspnea limited activities (0 to 18) was reported as 7.1 in the control group and 3.6 in the intervention arm (p=0.07).

One prospective cohort study evaluated a consultative model on a hemodialysis unit over a period of 6 months.[73] The other study evaluated the effect of a shared care model on a wider patient population over a time period ranging from 2 weeks to 9 months.[68] Both prospective cohort studies assessed dyspnea with the ESAS and each worsened with the intervention, although this was not clinically significant. In one cohort study, dyspnea changed from a mean of 0.34 +/- 1.06 at baseline to 1.06 +/- 1.95 (p=0.009).[73] In the other cohort study, dyspnea changed from a mean (SD) of 1.57 (2.63) to 1.75 (2.24).[68]

Since results were not clinically meaningful, we concluded that models for integrating palliative care were not more effective than usual care for dyspnea.

Multimodal Interventions

No studies evaluating multimodal interventions assessed dyspnea.

Fatigue

Models for Integrating Palliative Care

One RCT and two prospective cohort studies assessed the effect of models for integrating palliative care on fatigue.[68, 71, 73]

The RCT evaluated a consultative care model over a period of 6 months in patients with CHF.[71] One prospective cohort study evaluated a consultative model on a hemodialysis unit over a period of 6 months.[73] The other study evaluated the effect of a shared care model on a wider patient population over a time period ranging from 2 weeks to 9 months.[68]

The RCT assessed fatigue with the Patient-Reported Outcomes Measurement Information System Short Form 8a. There was a difference of -2 (95% CI, -3.6 to -0.4) between groups at 6 months (p=0.02), which is not clinically meaningful.

Both prospective cohort studies assessed fatigue with the ESAS, reporting inconsistent results. In one cohort, fatigue changed from a mean of 2.98 +/- 3.22 at baseline to 4.06 +/- 2.69 (p=0.02).[73] In the other cohort, fatigue changed from a mean (SD) of 5.49 (3.16) to 4.98 (2.52).[68]

Given that differences were not clinically meaningful, models for integrating palliative care were not more effective than usual care for fatigue.

Multimodal Interventions

No studies evaluating multimodal interventions assessed fatigue.

Concordance Between Patient Preferences and Care Received

Models for Integrating Palliative Care

One RCT assessed the effect of integrating social workers in a heart failure population on concordance between patient preferences and care received over a period of 6 months.[78] Concordance was assessed as the percentage of patients with improvement in prognostic alignment. This was defined as the revision of patient expectations of prognosis in a direction consistent with those of the treating physician. At 6 months, 26 percent of the usual care arm, compared with 94 percent of the intervention arm, had prognostic alignment (p<0.001).

We were unable to draw conclusions about the effect of models for integrating palliative care on concordance between patient preferences and care received, because there was only one small study with high risk of bias.

Multimodal Interventions

No studies evaluating multimodal interventions assessed concordance between patient preferences and care received.

Caregiver-Reported Outcomes

Health-Related Quality of Life

Models for Integrating Palliative Care

One RCT assessed the impact of models for integrating palliative care on caregiver quality of life.[79] This RCT assessed a telehealth intervention on caregivers of patients with heart failure over a period of 16 weeks. Quality of life was assessed with the Bakas Caregiver Outcomes

Scale (scores range from 15 to 105). The reported mean between-group difference at 16 weeks was -0.4 (95% CI, -5.1 to 4.3, p=0.88). This was unlikely to be clinically meaningful.

There may be little to no effect of models for integrating palliative care compared with usual care on caregiver quality of life.

Multimodal Interventions

No studies evaluating multimodal interventions assessed HRQOL in caregivers.

Symptoms of Depression

Models for Integrating Palliative Care

Two RCTs assessed the impact of models for integrating palliative care on caregiver symptoms of depression.[67, 79] The first RCT assessed a telehealth intervention on caregivers of patients with heart failure over a period of 16 weeks.[79] Symptoms of depression were assessed with the HADS. At 16 weeks, the reported mean between-group difference was 0.1 (standard error [SE], 0.5, p=0.86).

The second RCT assessed a model on caregivers and patients with Parkinson's disease and related disorders over a period of 6 months.[67] Symptoms of depression was also assessed with the HADS-depression scale. At 6 months, the reported mean difference was -0.9 (95% CI, -1.83 to 0.03, p=0.06).

Differences were not clinically meaningful, suggesting that models for integrating palliative care were not more effective than usual care for symptoms of depression.

Multimodal Interventions

No studies evaluating multimodal interventions assessed symptoms of depression in caregivers.

Symptoms of Anxiety

Models for Integrating Palliative Care

Two RCTs assessed the impact of models for integrating palliative care on caregiver symptoms of anxiety.[67, 79] The first RCT assessed a telehealth intervention on caregivers of patients with heart failure over a period of 16 weeks.[79] Symptoms of anxiety were assessed with the HADS. At 16 weeks, the reported mean between-group difference was -0.1 (SE, 0.5, p=0.88).

The second RCT assessed a model on caregivers and patients with Parkinson's disease and related disorders over a period of 6 months.[67] Symptoms of anxiety was also assessed with the HADS-anxiety scale. At 6 months, the reported mean difference was -0.43 (95% CI, -1.46 to 0.61, p=0.42).

Differences were not clinically meaningful, suggesting that models for integrating palliative care were not more effective than usual care for caregiver symptoms of anxiety.

Multimodal Interventions

No studies evaluating multimodal interventions assessed anxiety symptoms in caregivers.

Psychological Well-Being

Models for Integrating Palliative Care

One RCT assessed the impact of models for integrating palliative care on caregiver psychological well-being.[67] This RCT assessed a model on caregivers and patients with Parkinson's disease and related disorders over a period of 6 months. Psychological well-being was assessed with the Functional Assessment of Chronic Illness Therapy–Spiritual Well-Being Scale. At 6 months, the reported mean difference between groups was 1.79 (95% CI, -0.0 to 3.6, p=0.05).

There may be little to no difference in the effect of models for integrating palliative care on caregiver psychological well-being.

Multimodal Interventions

No studies evaluating multimodal interventions assessed psychological well-being in caregivers.

Burden, Impact, or Strain

Models for Integrating Palliative Care

Two RCTs assessed the impact of models for integrating palliative care on caregiver burden, impact, or strain.[67, 79] The first RCT assessed a telehealth intervention on caregivers of patients with heart failure over a period of 16 weeks.[79] Caregiver burden was assessed with the Montgomery-Borgatta Caregiving Burden Scale, broken down into 3 scales (objective, demand, and stress burdens). At 16 weeks, the reported mean between-group difference for the objective burden was 0 (SE, 0.5), p>0.99, for the demand burden -0.4 (SE, 0.4, p=0.35) and for the stress burden -0.4 (SE, 0.4, p=0.38).

The second RCT assessed a model on caregivers and patients with Parkinson's disease and related disorders over a period of 6 months.[67] Caregiver burden was assessed with the Zarit Burden Interview (ZBI-12). At 6 months, the reported mean difference -2.6 (95% CI, -4.58 to -0.61, p=0.01). We were unable to determine if this was clinically meaningful.

There may be little to no difference in the effect of models for integrating palliative care on caregiver burden, impact or strain.

Multimodal Interventions

No studies evaluating multimodal interventions assessed caregiver burden, impact, or strain.

Healthcare Utilization

Use and Length of Hospice Care

Models for Integrating Palliative Care

No studies evaluating models assessed use and length of hospice care.

Multimodal Interventions

One CT, reported in two articles, assessed the effect of multimodal interventions on use and length of hospice care.[24, 25] The study evaluated use and length of hospice care among a subset of deceased patients with completed Medicare claims data whom had identified as being at high

risk. The percentage of patients with at least one day in hospice was 55.3 percent in the intervention arm compared with 40.7 percent in the usual care arm [relative risk (RR) 1.36; 95% CI, 0.81 to 2.29; p=0.33]. Length of hospice stay was not statistically different between groups (51 vs. 29.3 days, p=0.43).

We were unable to draw conclusions about the effectiveness of multimodal interventions on use and length of hospice care, as only one study reported inconclusive results.

Hospitalizations

Models for Integrating Palliative Care

Four studies, reported in five articles, evaluated the effect of models for integrating palliative care on hospitalizations.[71, 72, 74, 75, 77] One study evaluated the effect of a model for integrating palliative care on rehospitalizations.[69]

Two RCTs evaluated the effect of a model for integrating palliative care on hospitalization.[71, 72] The first RCT evaluated clinician training/education combined with an integrated model of a nurse, social worker, palliative care specialist, and cardiologist providing symptom and psychosocial assessments compared with usual care over a period of 6 months in patients with CHF. There were no significant changes in the number of all-cause hospitalizations between the intervention group and the usual care group (p=0.61). The study reported individuals with one hospitalization and individuals with two or more hospitalizations. Among those with one hospitalization, 18 were in the intervention group and 30 were in the control group (RR 0.6; 95% CI, 0.35 to 1.03). Among those with two or more hospitalizations, 9 were in the intervention group and 6 were in the control group (RR 1.5; 95% CI, 0.55 to 4.11).[71]

The second RCT evaluated a collaborative care model of a nurse, primary care physician, cardiologist, and psychiatrist using home telemonitoring and patient self-management support in a heart failure population. The one-year hospitalization rates between the intervention group and the usual care group was similar between groups (29.4% vs. 29.9%, p=0.87).[72]

One CT, reported in two articles, evaluated patient-caregiver training/education combined with an integrated model of a social worker, nurse, chaplain, pharmacist, psychologist, art therapist, volunteer coordinator, and three physicians compared with usual care over a period of 12 months in patients with COPD, CHF, and cancer. The mean number of hospitalizations during 12 months (1.2 vs. 0.8, p=0.21) and the mean number of hospitalized days (6.3 vs. 4.3, p=0.38) was not different for the intervention group compared with the usual care group.[74, 75]

One CT consisted of a 6-session intervention delivered by social workers or health educators focused on health counseling, education, and care coordination in patients with CHF, COPD, cancer, or end-stage renal disease. In the prospective trial, inpatient admissions in the intervention group and control group at post-test, respectively, were 4.33 (SD 16.26) vs. 2.44 (SD 5.11, p=0.045).[77]

One RCT, evaluating the integration of a palliative care nurse practitioner supported by a palliative care physician into the care of heart failure patients, reported rehospitalization.[69] Compared with patients in the usual care group, the number of patients in the intervention group with a six-month rehospitalization rate for heart failure (30.7% vs. 29.3%, RR 1.05; 95% CI, 0.64 to 1.7), non-heart failure cardiovascular (16% vs. 10%, RR 1.2; 95% CI, 0.55 to 2.61), and non-cardiovascular (10.7% vs. 24%, RR 0.44; 95% CI, 0.21 to 0.96) did not differ from the usual care group.[69]

We were unable to conduct a meta-analysis, as two RCTs were missing either followup data or variability measurements. Models for integrating palliative care were not more effective than usual care for the outcome of hospitalizations.

Multimodal Interventions

One RCT assessed the effect of multimodal intervention on hospitalization.[26] The RCT evaluated a clinician training/education combined with an automatic trigger to initiate implantable cardioverter-defibrillators deactivation discussion among advanced heart failure patients (n=525). The mean number of hospital admissions within 24 months of study enrollment did not vary between intervention and control group (1.4 vs. 1.2, p=0.13).[26]

Our confidence is limited by only one study reporting this outcome, but results suggest that multimodal interventions had little to no effect on hospitalizations.

Advance Directive Documentation

Models for Integrating Palliative Care

Seven studies, reported in eight articles, evaluated the effect of models for integrating palliative care on advance directive documentation.[67, 70, 73-78]

Four RCTs evaluated the effect of models for integrating palliative care on advance directive documentation.[67, 70, 76, 78] The first RCT evaluated a social work integration model where social workers led patients through structured goals-of-care conversations over a period of 6 months (n=50). Advance directive documentation was reported as two different outcomes: percent of patients with any documentation of advance care preferences in electronic health records prior to death and percent of patients with physician-level documentation of advance preference that included hospice referral or end-of-life care.[78] The second RCT evaluated a six-session intervention focused on care coordination, physician support, health literacy, and end-of-life planning over a period of 6 months in patients with COPD, CHF, and cancer.[76] The third RCT evaluated a five-month intervention where palliative care consultation was provided by an interdisciplinary team of nurse practitioner, physician, social worker, and chaplain to patients with heart failure who were recruited during hospitalization.[70] The last RCT evaluated a year-long integrated outpatient palliative care delivered by a neurologist, social worker, chaplain, nurse, and palliative medicine specialist to patients with Parkinson's disease and related disorders every 3 months.[67]

We conducted a meta-analysis with all four RCTs using percent completion of advance directive (AD) documentation at 6 months. All studies provided group differences. Based on the overall pooled results from the meta-analysis, patients in the intervention group had a 62.0 percent statistically higher chance of having AD documentation compared with patients in standard care (Relative Risk, 1.620 CI, 1.350 to 1.945, I-squared=0.0%) (Figure 4).

Two CTs, reported in three articles, evaluated the effect of models for integrating palliative care on AD documentation.[74, 75, 77] The first CT evaluated patient-caregiver training/education combined with an integrated model of a social worker, nurse, chaplain, pharmacist, psychologist, art therapist, volunteer coordinator, and three physicians compared with usual care over a period of 12 months in patients with COPD, CHF, and cancer.[74, 75] Advance directive documentation was reported as percent of patients with Durable Power of Attorney for Health Care (DPOA-HC)

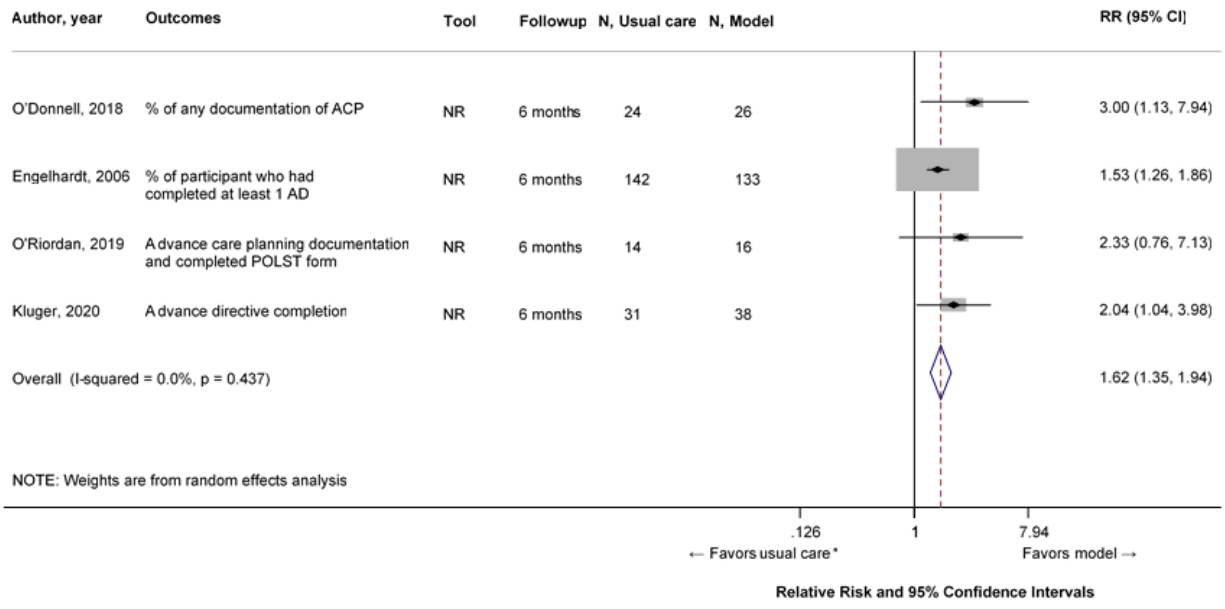
paperwork completed. The percent of patients completing DPOA-HC paperwork was 40 percent for the intervention and 38 percent for the control group (RR 1.92; 95% CI, 0.74 to 5; p=0.91).

The second CT consisted of a six-session intervention delivered by social workers or health educators focused on health counseling, education, and care coordination in patients with CHF, COPD, cancer, or end-stage renal disease.[77] Advance directives were reported as the patient's formulation of ADs, including the designation of a proxy or living will, and the days to formulation of advance care directives. Patients in the intervention group were 2.22 times (95% CI, 1.62 to 3.05) more likely to formulate an AD compared with the usual care group (47% vs. 21%, p<0.05).

One prospective cohort study evaluated an embedded model of palliative care physician consultations on a hemodialysis unit.[73] Advance directive documentation was reported as advance directives in medical records. Advance directives increased from 41 percent preintervention to 46 percent postintervention (p=0.22) during the study period of 6 months.

Compared with the results of our meta-analysis, the results of the two CTs are consistent in reporting greater AD completion among patients in the intervention group compared with those in the usual care group, although the results are not statistically significant. Based on the results of our meta-analysis and consistent results from additional studies, we concluded that models for integrating palliative care were more effective than usual care for increasing advance directives documentation (SOE: Moderate).

Figure 4. Meta-analysis of the effects of models for integrating palliative care on increasing advance directive documentation in patients with noncancer serious chronic illness compared with usual care



ACP=advanced care planning; AD=advanced directive; CI=confidence interval; N=sample size; POLST=Portable Medical Orders; RR=relative risk; SMD=standardized mean difference

*Relative risk over 1 for advance directive outcomes favors the intervention model over usual care.

Multimodal Interventions

One RCT evaluated a clinician training/education combined with an automatic trigger to initiate implantable cardioverter-defibrillators deactivation discussion among advanced heart failure patients.[26] Advance directive documentation was assessed as the percent of chart documentation of advance directives, including healthcare proxy, living will, or do-not-resuscitate orders. Compared with the usual care group, those receiving the intervention did not have notable differences in the percent of chart documentation of advance directives (57.9% vs. 52.6%, p=0.37). This outcome is considered indirect as is an intermediate, non-patient reported outcome, but it was reported in a large trial with low risk of bias. Multimodal interventions may have little to no effect on advance directive documentation (SOE: Low).

Costs and Resource Use

Models for Integrating Palliative Care

Three CTs and one prospective cohort study, reported in five articles, assessed the effect of models for integrating palliative care on costs and resource use.[68, 74-77]

In the first CT, costs were reported as mean charges per patient for medical center services that include clinic visits, urgent care visits, emergency department (ED) visits, and hospital stay. These charge data were obtained from computerized billing records. The mean charge per patient for all medical center services for the intervention group was $47,211 (SD, $73,009) for intervention patients and $43,338 (SD, $69,647) for the usual care group (p>0.05).[74, 75]

In the same CT, resource use tabulated visits to general medicine clinics, specialty clinics, urgent care clinics, and the ED. The mean number of general medicine clinic visits was 3.1 points less for patients in the intervention group compared with those in the usual care group (7.5 vs. 10.6, p=0.03). The mean number of urgent care clinic visits for patients in the intervention group was half the number compared with those in the usual care group (0.3 vs. 0.6, p=0.03).[74, 75]

In the second CT, costs were assessed at the patient-level six months prior to enrollment and at 3 months and 6 months post enrollment, and abstracted from the Veterans Affairs (VA) medical center database. Costs included direct healthcare costs associated with inpatient and outpatient care, stays in nursing home, and inpatient hospice, in addition to ancillary costs of diagnostic services, medication, durable medical prosthetics, care provided in non-VA settings, and administrative overhead, including salary (i.e., described as also including the cost of the intervention, although details were not specified). At 6 months post-enrollment, the mean cost per patient in the intervention group was $12,123 (SD $16,036) and the mean cost per patient in usual care group was $16,295 (SD $28, 492). The difference in mean costs between the groups was $4,172 (SD $12,456) (p=0.29) (mean between group difference [MBGD] -3424.42, 95% CI, -13519.98 to 6671.14). The study did not report resource use.[76]

In the third CT, costs were not reported. Resource use tabulated mean number of hospital stays, ED visits, home health visits, outpatient visits, radiology tests, laboratory tests, and medication. Compared with the usual care group, patients in the intervention group had 2.59 more outpatient visits [32.01 (SD 25.05) vs. 29.42 (SD 25.52), analysis of variance (ANOVA) F=1.40]. Compared with the usual care group, patients in the intervention group had 1.66 fewer ED visits [3.69 (SD 6.14) vs. 5.35 (SD 12.87), ANOVA F=3.60]. Adjusting for baseline variables, age, and sex, the post-test difference between the number of medical services used between the intervention group and the usual care group was not significant.[77]

The prospective cohort study only reported resource use as mean ED visits per week in the year 2009 (baseline) and 2010 (enrollment period).[68] The mean ED visits per week decreased significantly between 2009 (0.07 visits) and 2010 (0.04 visits) after enrollment (p=0.001).

Models for integrating palliative care report different metrics to assess costs and resource use and this makes it difficult to compare results. Charge data using patient bills serve as a proxy for costs and are not reflective of actual costs incurred by the patient in the CT.[74] Costs reported in the RCT do not capture long-term evaluation and varying outcomes associated with diagnosis that impact differences between the intervention group and the usual care group.[76] Reporting metrics for resource use was also inconsistent in terms of type of health services used and frequency of use to draw meaningful conclusions.[74, 75, 87] Studies varied widely in reporting metrics of outcomes related to cost and resource use and did not generally report intervention costs and, as such, we were not able to draw conclusions about the effect of models for integrating palliative care versus usual care on cost and resource use.

Multimodal Interventions

One CT, reported in three articles, assessed the effect of multimodal interventions on cost and resource use.[24, 25, 86].

The study evaluated the Serious Illness Care program, a communication intervention, on total monthly medical expense using claims data among two cohorts of deceased patients: 1) those in intervention and comparison clinics, regardless of conversation status and 2) those in the intervention clinics with and without conversation.[86] The study did not account for the costs of the intervention. Comparing those in intervention to comparison clinics, total monthly medical expenses were not statistically significantly different at baseline, seven to twelve months before death, (baseline: $4,006 vs $4476, p=0.67) and at last six, three, and one month of life (last six month: $7,345 vs $8,867, p=0.16; last three months: $8,994 vs $10,504, p=0.45 last one month: $12,602 vs $13,563, p=0.77). These differences may be clinically meaningful, but cost data was incomplete. We conclude that multimodal intervention may have little to no effect on cost and resource use compared with usual care.

Adverse Effects

Medication Side Effects

No studies of models for integrating palliative care or multimodal interventions reported medication side effects.

Dropouts Related to the Intervention

No studies of models for integrating palliative care or multimodal interventions reported dropouts related to the intervention.

Key Subquestion c. How Have They Been Implemented?

Key Question 1c. How have prediction models, tools, and triggers for identifying when and which patients with serious life-threatening chronic illness or conditions in ambulatory settings could benefit from palliative care been implemented? What is the evidence for how, when, and for which patients they could best be implemented in care?

We identified no studies for this Key Question.

Key Question 2c. How have educational materials and resources about palliative care and palliative care options for patients with serious life-threatening chronic illness or conditions and their caregivers in ambulatory settings been implemented? What is the evidence for how, when, and for which patients and caregivers they could best be implemented in care?

We identified no studies for this Key Question.

Key Question 3c. How have palliative care shared decision-making tools been implemented for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers? What is the evidence for how, when, and for which patients and caregivers they could best be implemented in care?

Key Points

How have they been implemented?

- Shared decision-making tools evaluated for implementation all focused on advance care planning.
- Studies addressed heart failure, ESRD, and COPD populations.

How could they best be implemented in care?

- Patients and caregivers preferred advance care planning discussions grounded in patient and caregiver experiences of illness, rather than general conversations about the end of life.
- Clinicians preferred advance care planning shared decision-making tools that were time-efficient and included structured scripting.

When could they best be implemented?

- Patients and caregivers felt that timing of advance care planning conversations should be individualized to the specific patient and caregiver.

Description of Included Studies

We identified five studies that used different approaches to explore how, when, and for which patients palliative care shared decision-making tools could best be implemented. These studies primarily described the implementation of tools or interventions that facilitated advance care planning discussions,[50-52] how clinicians document these discussions,[88] and systematic efforts to promote interdisciplinary collaboration among diverse treating

providers (Table 18). [89] The studies included patients (2 studies, n=18),[50, 51] caregivers (2 studies, n=38, such as family members),[51, 52] and nonpalliative care ambulatory clinicians (physicians and nurse practitioners) (3 studies, n=47).[50, 88, 89] One study conducted qualitative observations[50] and four studies conducted qualitative interviews[51, 52, 88, 89] (see Appendix D for full study characteristics).

Shared decision-making tools were considered related to the following conditions: COPD (1 study),[50] general populations with serious illnesses (1 study),[88] advanced heart failure [with Left Ventricular Assist Devices (LVADs)] (1 study),[51] and end-stage renal disease (ESRD) on dialysis (2 studies).[52, 89] One ESRD study was linked to a quantitative effectiveness evaluation of the intervention.[52] Two studies were rated as low quality because the overall research methodology, analysis of data, and interpretation of results were insufficiently described.[50, 89] The remaining three studies were classified as high quality.[51, 52, 88] All studies used thematic analysis. Although one study reported "grounded theory" as their analytic technique, this may be more appropriately described as thematic analysis, because the authors conducted analyses for the development of themes.[89] (see Results Appendix D for study details).

Table 18. Characteristics of qualitative studies for shared decision-making tools

Author, Year	Study and Participant Characteristics and Funding	Intervention Description
Dillon, 2017[88]	n=13 • Clinicians, single-center, outpatient multispecialty group practice • Cardiology, pulmonology, oncology, and primary care clinicians • Multiple funding sources	No intervention evaluated. (Study described the process of how clinicians currently incorporate documentation of advance care planning into the electronic health record.)
Uhler, 2015[50]	n=12 (4 patients, 8 physicians) • Multi-site, outpatient pulmonary clinic and outpatient pulmonary rehab • Pulmonologists and patients with chronic obstructive pulmonary disease (COPD) • Government funding	The Informed Together decision aid is a Web-based platform that projects survival outcomes using patient age and disease severity that can be entered by a patient or clinician. After the information is entered, several pages are produced, including personalized survival estimates for Full Code vs. Do Not Resuscitate (DNR) advanced directive status and a suggested script to discuss the topics of prognosis and planning in case of a COPD exacerbation.
Metzger, 2016[51]	n= 28 (14 patients, 14 caregivers) • Single-center, outpatient Left Ventricular Assist Device (LVAD) clinic • LVAD patients and caregivers • Multiple funding sources	Advance Care Planning Intervention: Usual care with SPIRIT-HF intervention: one-hour, structured discussion facilitated by a Ph.D.-prepared nurse, trained in the original SPIRIT intervention, with patients with LVADs and their designated caregiver decision-makers. Discussion aimed to elicit patient and caregiver understanding of the patient's heart failure, the LVAD, prognosis, and life-sustaining treatment. Using this understanding, the nurse facilitated discussion between patient and caregiver regarding different end-of-life scenarios.
Song, 2017[52]	n=24 • Multi-site, outpatient dialysis clinics • Bereaved caregivers of dialysis patients • Government funding	Advance Care Planning Intervention: the SPIRIT intervention included two sessions delivered by a trained nurse. The nurse assessed cognitive, emotional, and spiritual/religious aspects of patient and caregiver understanding of the patient's illness, prognosis, and end-of-life care. The nurse used this information to provide individualized information about effectiveness of life-sustaining treatment for people on dialysis, helping the patient examine their own values about life sustaining treatment, and facilitated a discussion between the patient and caregiver to prepare the caregiver for decision-making.
O'Hare, 2016[89]	n=26 providers • Multi-site, Veterans Affairs Healthcare System • Cardiology, Geriatrics, Intensive Care, Nephrology, Palliative Care, Physiatry, Primary Care, Social Work, Vascular Surgery, Nutrition • Government funding	• No intervention evaluated. (Elicit perspectives on advance care planning of multidisciplinary providers who care for patients with advanced kidney disease)

COPD = chronic obstructive pulmonary disease; LVAD = left ventricular assist device; DNR = do not resuscitate; SPIRIT= Sharing Patients' Illness Representation to Increase Trust.

Table 19. Integrative review results on qualitative evidence for how, when, and for which patients and caregivers shared decision-making tools could best be implemented in care

Factors for Implementation of Shared Decision-Making Tools	Clinician/Stakeholder and Patient/Caregiver Perceptions
External factors	Not addressed
Organizational factors	Concerns about implementation during routine care owing to time constraints
Organizational characteristics	Not addressed
Collaboration, resources and leadership	Not addressed
Intervention and implementation characteristics	Intervention: • Preferences for grounding in patient and caregiver experiences of illness, rather than general conversations about the end of life* • Providing information about the life-limiting nature of the illness* • Acknowledge the caregiver's role and empower and prepare them and open communication with patient* • Patients/caregivers: individualize timing to preferences*; clinicians: at time of medical stability • Should be time-efficient, specific, and succinct Implementation: • Integration into clinical workflow • Need for standardized workflows
Clinician/team characteristics	• Advance care planning should be conducted by clinician who knows the patient best • Systematic efforts to promote interdisciplinary collaboration among diverse clinicians
Patient/caregiver characteristics	Not addressed

The studies we identified evaluated the implementation of advance care planning tools alongside clinical workflows and assessed overall patient, caregiver, and clinician experiences of advance care planning experiences (Table 19). Two studies discussed clinicians' perspectives on incorporating advance care planning into their clinical processes and in interactions with patients to improve the delivery of care.[88, 89] Two studies evaluated iterations of the Standard Protocol Items: Recommendations for Interventional Trials **(**SPIRIT) intervention, a nurse-led intervention consisting of nurse-facilitated discussions with patients and their caregivers regarding various advance care planning topics.[51, 52] SPIRIT-HF adapted the original SPIRIT intervention targeting dialysis patients and caregivers for use among LVAD patients and caregivers. The remaining study examined the acceptability of a Web-based decision-making aid providing individualized survival estimates and suggested scripting to discuss advance care planning and prognosis.[50]

Below are findings from the patient, caregiver, and clinician perspectives as to how, when, and for which patients and caregivers shared decision-making tools could be implemented.

How. In terms of how shared decision-making tools should be implemented, patients and caregivers reported that sharing the story of their serious illness was a positive and essential part of the experience in the intervention, focusing the discussion on the patient's and caregiver's experiences, rather than starting by talking about death.[51] Patients and caregivers who experienced SPIRIT or SPIRIT-HF felt that the intervention brought peace of mind by allowing them to express and clarify their wishes and ensuring that they were prepared for future care decisions.[51, 52] Further, caregivers saw the SPIRIT intervention as an opportunity for discussion of topics that had previously been avoided (e.g., death, life-sustaining treatments, acceptable/unacceptable outcomes, end-of-life

preferences).[52] In addition to perceived improvements in HRQOL among caregivers who received the intervention, caregivers also perceived that SPIRIT provided them with information about the life-limiting nature of the patient's illness, prompted them to consider circumstances in which life-sustaining treatments may/may not be beneficial, and acknowledged the caregiver's role in making decisions on behalf of the patient's wishes. Caregivers additionally reported that this empowered them and opened lines of communication with the patient, while also incorporating other family members into care decisions, resulting in caregivers feeling better prepared to make decisions during the time preceding end-of-life decision-making and taking into account their loved one's wishes.[52] Clinician interviews highlighted the need for systematic and standardized workflows that support ACP discussions and documentation, including improving interdisciplinary collaboration between various providers caring for patients with serious illness.[88, 89]

When. Several studies evaluated the best timing for the implementation of palliative care shared decision-making tools. In one study, patients and caregivers felt that advance care planning discussions should take an individualized approach and that the best timing may vary by person.[51] Clinicians in this study felt that advance care planning conversations should be initiated during a time of medical stability, identified by the clinician who sees the patient most frequently; the clinician has a trusting relationship with the patient and should act as the "quarterback" who is responsible for advance care planning for that patient.[51] Similarly, as described through the SPIRIT and SPIRIT-HF interventions, patients and caregivers recommended integration of the advance care planning discussion into the normal clinical workflow of the LVAD and dialysis clinics but did not detail when, how frequently, or by whom these discussions should be conducted and documented.[50] Clinicians identified the need for standardized workflows to incorporate discussions, such as those in the SPIRIT interventions, into routine care.[50] Overall, clinicians felt advance care planning tools are acceptable but should be time efficient, specific, and succinct, and also felt that clinician education would enhance successful implementation.[50, 88]

For Which Patients. The studies we identified evaluated the implementation of palliative care shared decision-making tools during routine ambulatory clinical care for patients with COPD,[50] advanced or end-stage renal disease,[52, 89] and advanced heart failure.[51]

Grounding advance care planning discussions in patient and caregiver experiences with their illness, rather than as a general discussion about death, was acceptable to patients and caregivers.[51, 52] Patients and caregivers felt that the timing of these conversations should be individualized to specific patients and caregivers;[51] some expressed a desire for initiation of these conversations earlier in the disease course.[51] Clinicians found these tools acceptable when the tools were time efficient and included structured scripting, but they had concerns about implementation during routine ambulatory care owing to time constraints within the visits or lack of systematic implementation.[50, 89]

KQ4c. How have palliative care training and educational materials (with or without other intervention components) for nonpalliative care clinicians caring for patients with serious life-threatening chronic illness or conditions in ambulatory settings been implemented? What is the evidence for how, when, and for which clinicians they could best be implemented in care?

Key Points

- Equipping clinicians to provide advance care planning training to their physician colleagues was perceived as acceptable.
- Clinicians reported that scripting advance care planning guides facilitated initiation of patient-centered conversations.

Description of Included Studies

We identified one study that evaluated clinicians' self-reported learning experiences following a clinician-led training course using the Serious Illness Conversation Guide.[64] This study used a "train-the-trainer" model, which consisted of training clinicians (n=22) within three large healthcare systems to subsequently train nonpalliative care clinicians (n=297) to use the Guide within their respective institutions (Table 20) (see Results Appendix D for full study characteristics). We judged this study as low quality because the overall research methodology, analysis of data, and interpretation of results were insufficiently described.

Table 20. Characteristics of qualitative studies for shared decision-making tools

Author, Year	Study and Participant Characteristics and Funding	Intervention Description
Paladino, et al., 2019[64]	n=22 trainers, n=297 • Clinicians trained, multi-site, multiple specialties • Cardiology, radiation oncology, oncology, geriatrics, pediatrics, family medicine, primary care/internal medicine, palliative care, critical care/ICU, pulmonary, nephrology, other/unknown • Industry funding	• Trainer Training: The two-day, train-the-trainer curriculum was based on best educational practices and adult learning theories, including attention to knowledge, attitudes, and skills-oriented practice with feedback. The goal was to prepare faculty trainers to deliver a predesigned, structured, 2.5- to 3-hour clinician training on serious illness communication. • Trainee Training: Led by the trained clinicians from within the respective institution, the clinician training teaches clinicians to have conversations about patients' values, goals, and prognoses using a scalable tool, the Serious Illness Conversation Guide. The training involved interactive methods, including reflection, demonstration and debriefing, cognitive maps, and skills practice with feedback.

ICU = intensive care unit.

When clinicians were equipped to provide training to their clinician colleagues within the same institution, they reported that they felt more comfortable initiating advance care planning discussions following the training. Clinicians reported that the scripting of the Serious Illness Guide allowed for easier initiation of conversations while facilitating efficient, natural, patient-centered conversations. Physicians, advanced practice clinicians, nurses, social workers, and chaplain trainers found this training model acceptable to use in their respective ambulatory practices.

KQ5c. What are components of models and multimodal interventions for integrating palliative care in ambulatory settings? What models and multimodal interventions have been implemented for key subpopulations? What components and characteristics of these models and multimodal interventions contribute to their effective implementation? What is the evidence for how, when, and for which patients they could best be implemented in care?

Key Points

What are components of models and multimodal interventions for integrating palliative care?

- Models for integrating palliative care and multimodal interventions evaluated for implementation included strategies to facilitate shared decision-making and communication to address symptoms and goals of care, designated roles and responsibilities for each team member, and structured workflows to promote integration and address followup care.

What has been implemented for key subpopulations?

- Models for integrating palliative care and multimodal interventions have been evaluated for implementation among patients with COPD, ESRD, and advanced heart failure, and in general primary care populations.

How could they best be implemented in care?

- Patients valued clinicians who understood the unique considerations of their illness trajectory in providing individualized care.
- Patients perceived cost of care, scheduling additional visits, and traveling to the clinic as key barriers to implementation.
- Clinicians preferred implementation with clear goals, objectives, and roles for each clinician involved, and accounting for the specific needs of key stakeholders.
- Clinicians perceived that implementation requires: 1) patient-centered needs assessments and performance measures, 2) collaboration among clinicians and local leaders, and 3) adequate financial support.

When could they best be implemented?

- Patient perceptions of appropriate timing to initiate palliative care varied, but patients did not have concerns about palliative care being initiated too early.

Description of Included Studies

We identified 10 studies investigating models for integrating palliative care and multimodal interventions in ambulatory settings from both patient and clinician perspectives (Table 21, Tables 22 and 23 reflect integrative review results on the qualitative evidence for components and characteristics of models for integrating palliative care in ambulatory settings and integrative review results on the qualitative evidence for how, when and for which patients models for integrating palliative care could best be implemented). These studies evaluated barriers and facilitators from both practical and implementation frameworks, in addition to the overall patient experience. Of the ten included studies, five were intervention studies: one study was a shared care model,[80] one study involved social workers in care delivery,[83] two studies used consultative

care models,[81, 82] and one study was a multimodal intervention of clinician training/education with a trigger.[84]

The studies included patients (5 studies, n=146),[80-82, 90, 91] nonpalliative care ambulatory physicians (3 studies, n=51),[84, 92, 93] and clinical team members on a palliative care advisory group (n=11).[94] One study[83] was conducted with clinicians, patients, and caregivers; however, the total number of people who answered open-ended questions was not reported. One study conducted qualitative observations and evaluated open-ended survey responses[83] and nine studies conducted individual qualitative interviews[80-82, 84, 90-94] (see Results Appendix D for full study characteristics).

All studies used some variation of thematic analysis. One study reported "modified grounded theory," which, on further examination, appeared to be better characterized as a thematic analysis.[90] and another study reported "constant comparison derived from grounded theory" for the development of themes.[91] Seven of the ten articles were rated as high quality.[80, 83, 84, 91-94] Three articles were rated as low quality because the overall research methodology, analysis of data, and interpretation of results were insufficiently described, thus we could not determine how well the conclusions were supported by the analysis and interpretation of the data.[81, 82, 90]

Table 21. Characteristics of qualitative studies for models and multimodal interventions

Type	Author, Year	Study and Participant Characteristics and Funding	Intervention Description
Shared Care Models	Bekelman, 2014[80]	n=17 patients • Multi-site, hospital and hospital outpatient clinic • Patients with advanced heart failure [New York Heart Association (NYHA) III/IV], hypertension, and COPD Government funding	• No control group. • Collaborative Care to Alleviate Symptom and Adjust to Illness (CASA): Clinician training/education combined with a palliative care model. Routine, structured symptom assessment and management by nurse (6 sessions, 1 to 2/month), routine, structured psychosocial assessment and management by social worker via telephone (6 sessions), collaborative care team including palliative care specialist and cardiologist provided care review and supervision. Nurse was trained in assisting with communication (1 hour), motivational interview (4 hours), and guidelines on symptoms (3 hours), social worker received training on psychosocial intervention training and supervision on followup visits (8 hours). • Model type: Shared Care Model.
Involving Care Coordinators/Social Workers In Care Delivery	Goff, 2019[83]	n=Unclear number of participants • Multi-site, dialysis clinics • ESRD patients on dialysis and their surrogates Government funding	• Intervention: Communication intervention in which nephrologists and social workers communicated prognosis and advance care planning in face-to-face initial meetings with the patient, caregiver, and social worker, followed by monthly social work encounters for 18 months. • Model Type: Involving Care Coordinators/Social Workers in Care Delivery
Consultative Care Models	Long, 2014[81]	n=13 patients • Single-site, pulmonary specialty clinic • Patients with COPD Nonprofit and government funding	• Intervention: An advance practice nurse provided palliative care for people with COPD already receiving COPD-focused treatment. This nurse evaluated and treated participants' dyspnea, anxiety, and depression using usual pharmacologic and nonpharmacologic interventions appropriate for palliative care. Via weekly calls to participants, between appointments, the advance practice nurse monitored symptoms and tolerance of treatments, relaying this and treatment-related decision information to clinical co-investigators. • Model Type: Consultative Care Model
	Rabow, 2003[82]	n=35 patients • Single-site, primary care • COPD, CHF, and cancer patients Nonprofit funding	• Intervention: Interdisciplinary palliative care team providing outpatient palliative care consultation, case management, psychological support, chaplaincy, caregiver training, medication review, and support groups. • Model Type: Consultative Care Model
	Lakin, 2019[84]	n=17 primary care clinicians • Multi-site, primary care clinics • Primary care physicians, nurses, and social workers Nonprofit funding	• Intervention: The Serious Illness Care Program uses workflow innovations, clinician training, and clinical tools to improve serious illness communication. This methodology selects patients for serious illness conversations, which triggers mechanisms to remind clinicians to have such conversations, and electronic medical record documentation support. The program's core clinical tool, the Serious Illness Conversation Guide, provides a framework for best communication practices. • Multimodal intervention: Clinician training/ education plus triggers
Other, Non-Interventional Studies	Nowels, 2016[92]	n=20 clinicians • Multi-site, primary care, • Primary care clinicians • Nonprofit funding	• No intervention evaluated. (Perceptions of palliative care in primary care)

Type	Author, Year	Study and Participant Characteristics and Funding	Intervention Description
	Scherer, 2018[94]	n=>57 key stakeholders • Single-site, outpatient kidney clinic • Nephrologists, dialysis nurses and social workers, office staff, hospitalists, administrators, vascular surgeons, cardiologists, other transplant team members • No funding	• No intervention evaluated. (Using participatory research to develop an outpatient integrated nephrology and palliative care program)
	Bekelman, 2016[93]	n=17 clinicians and health system leaders • Multi-site, Veterans Health Administration, • Primary care, cardiology, ambulatory care, geriatrics, palliative care, mental health, and health system leaders within the Veterans Health Administration • Government funding	• No intervention evaluated. (Evaluating collaborative primary care and palliative care model)
	Hobler, 2018[90]	n=48 patients • Single-site, cystic fibrosis clinic • Cystic fibrosis patients • Nonprofit funding	• No intervention evaluated. (Evaluating palliative care and advance care planning needs and clinicians' potential roles)
	Bekelman, 2011[91]	n=52 (33 patients and 19 caregivers) • Multi-site, geriatrics and cardiology outpatient clinics • Patients with heart failure (NYHA II-IV) and their surrogates • Government and nonprofit funding	• No intervention evaluated. (Describing HF patients' and their surrogates' major concerns and needs and exploring whether, how, and when palliative care would be useful to them)

NYHA = New York Heart Association; COPD = chronic obstructive pulmonary disease; CHF = congestive heart failure; ESRD = end-stage renal disease; CASA = Collaborative Care to Alleviate Symptoms and Adjust to Illness; HF=heart failure.

Table 22. Integrative review results on the qualitative evidence for components and characteristics of models for integrating palliative care in ambulatory settings

Key Components of Delivery of Integrated Palliative Care	Patient/Caregiver Perceptions of Key Components of Delivery of Integrated Palliative Care	Clinician/Stakeholder Perceptions of Key Components of Delivery of Integrated Palliative Care
Introducing palliative care	• Varied: preference for the intervention to be provided after diagnosis vs. beginning of the end of life	• Should be provided to terminally ill patients or preterminal stages
Communication	• Facilitating better communication about difficult issues • Listening with compassion • Feel heard and be "seen" • Involving family caregivers to help patients and families adjust to illness	• Paying special attention to clinician-patient relationships • Clearly structuring interventions aiming to change the way the system drives serious illness communication

Key Components of Delivery of Integrated Palliative Care	Patient/Caregiver Perceptions of Key Components of Delivery of Integrated Palliative Care	Clinician/Stakeholder Perceptions of Key Components of Delivery of Integrated Palliative Care
Addressing symptoms	Symptoms surveys were burdensome and repetitive	• Questionnaires to be more specific to conditions • Consider the appropriateness of certain questions for specific illnesses • Concerns about taking opioids • Address unmet needs
Psychosocial care	Not addressed	Not addressed
Care planning	Clinician who understands the context around their illness and its trajectory	Not addressed
Followup	• Obtaining social services that patients already qualify for • Able to offer solutions to individual concerns	Not addressed

Table 23. Integrative review results on the qualitative evidence for how, when and for which patients models for integrating palliative care could best be implemented*

Factors for Implementation of Models	Clinician/Stakeholder and Patient/Caregiver Perceptions
External factors	Not addressed
Organizational factors	• Driving to the clinic as a barrier; coordinating visits to correspond with other clinic visits • Additional ACP training for both social workers and physicians, including interprofessional training
Organizational characteristics	• Using existing practice improvement models, strategies, and prioritization
Collaboration, resources, and leadership	<u>Collaboration:</u> • Creating shared ownership • Understanding of specific stakeholder needs • Paying special attention to interprofessional relationships <u>Resources</u>: • Lack of clinician time • Cost of paying for visits • Difficulty scheduling sessions within busy schedules • Need to justify any additional personnel costs <u>Leadership</u>: • Collaborate with local leaders to align palliative care with local programs
Intervention and implementation characteristics	<u>Intervention:</u> • Clarify goals of collaborative care • Potential tools include performance measures, registries, needs assessments, decision aids, care management, coaches • Phone structure of an intervention was helpful* <u>Implementation:</u> • Address stakeholder needs and relationships, including involving in decisions about processes early in implementation • Clarify roles, responsibilities, and costs of outpatient palliative care vs. primary and specialty care

Factors for Implementation of Models	Clinician/Stakeholder and Patient/Caregiver Perceptions
Clinician/team characteristics	• Development of a dedicated, interdisciplinary team as potentially being beyond the capabilities of some healthcare institutions • Including APNs was feasible and patients found them beneficial* • Patients saw nurses as advocates*
Patient/caregiver characteristics	Not addressed

*Results from patient/caregiver studies
ACP = advance care planning; APNs = advanced practice nurses.

Components of Models or Multimodal Interventions for Integrating Palliative Care in Ambulatory Settings

Four studies investigated the feasibility and acceptability of implementing different models: 1) Collaborative Care to Alleviate Symptoms and Adjust to Illness (CASA) among patients with COPD, advanced heart failure, and hypertension, to better integrate psychosocial and symptom-focused care into chronic care, using a shared care model,[80] 2) Comprehensive Care Team (CCT) intervention for outpatients actively pursuing treatment of advanced illness, which provided multiple palliative care consults for the primary care clinician in addition to advance care planning, psychosocial support, and family caregiver training for patients with a palliative care model,[82] 3) an Advanced Practice Nurse (APN)-led intervention which included monthly visits by the APN and weekly phone-based symptom monitoring to assess and treat dyspnea, anxiety, and depression using "usual palliative care pharmacological and nonpharmacological interventions" guided by patient preferences using a consultative model,[81], and 4) the Shared Decision-Making and Renal Supportive Care" (SDM-RSC), which involved social workers longitudinally with a focus on communication and advance care planning for patients with end-stage kidney disease on hemodialysis.[83] In addition, one study evaluated a multimodal intervention, the Serious Illness Care Program, among primary care clinicians (physicians, care coordination nurses, and social workers) to use workflow innovations, clinician training, and triggers to improve serious illness communication.[84]

Components of Models for Integrating Palliative Care or Multimodal Interventions That Contribute to Effective Implementation

Patients

One study identified several simple and low-resource components of an intervention that were perceived to be useful and may be offered by non-medical personnel: 1) obtaining social services that patients already qualify for under existing funding mechanisms, 2) facilitating better communication about difficult issues, and 3) offering patients the simple gift of listening with compassion.[82] In another study, patients indicated that they want to feel heard and be "seen," to be instructed by a clinician who understands the context around their illness and its trajectory and who is able to offer solutions to individual concerns.[90] Patients and caregivers described the importance of programs involving family caregivers, focusing on helping patients and families adjust to both the limitations of and future of the illness, stressing the need to provide symptom relief that complements disease-specific strategies.[91]

The interventions delivered by Registered Nurses (RNs), APNs, or social workers were feasible and patients perceived them to be beneficial.[80, 81, 91] Patients were satisfied with the phone structure of the intervention, perceiving such structure as generally helpful, although they

also noted that the symptom surveys were burdensome and repetitive.[80] Among interventions led by RNs or APNs, patients saw the as advocates.[80, 81]

The studies also identified components of models that patients perceived to hinder implementation. In particular, COPD patients wanted questionnaires to be more specific to COPD conditions, wanted the intervention to be longer, and felt that there were "inappropriate" questions about sex and COPD.[81] In another study, patients similarly commented on the structure of the survey, which they generally deemed as being burdensome and repetitive.[80] Patients identified a variety of barriers to participation, which included lack of clinician time; difficulty scheduling sessions within busy schedules; and driving to the clinic for study visits, which was recommended to correspond with regular clinic visits to ease the burden of travel.[81] Additionally, patients' concerns about both taking opioids and the cost of paying for pulmonary rehabilitation and palliative care clinic visits influenced their decision to continue palliative care after the close of the study.[81]

Clinicians

Studies identified four key components that contributed to clinicians' perceptions of effective implementation of models for integrating palliative care: (1) clarifying the goals of collaborative care and creating a shared ownership,[94] (2) establishing clear professional roles and responsibilities,[84] (3) paying special attention to specific stakeholder needs and relationships,[84, 94] and (4) clearly structuring interventions aiming to change the way our system drives serious illness communication.[84] In another study, however, clinicians noted that the development of a dedicated, interdisciplinary team of clinicians and volunteers is potentially beyond the capabilities of some healthcare institutions.[82]

We summarized findings from the patient, caregiver, and clinician perspectives as to how, when, and for which patients and caregivers the models or multimodal interventions could be implemented.

How. From the clinician perspective, one study highlighted several key barriers and facilitators to implementation, noting that future efforts to scale up and implement the SDM-RSC intervention could benefit from additional ACP training for both social workers and nephrologists, including interprofessional training.[83] Another study described organizational factors that could influence the adoption and scale-up of outpatient palliative care in chronic advanced illness, using the example of heart failure.[93]

To effectively adopt and scale outpatient palliative care, they identified the need to 1) develop performance measures for patient-centered care and outcomes, 2) justify any additional personnel costs, 3) communicate and coordinate with other clinicians, especially primary care practitioners (PCPs), 4) collaborate with local leaders to align palliative care with local programs, and 5) clarify the roles and responsibilities of outpatient palliative care versus primary and specialty care for disease management in advanced chronic illness. Clinicians described feeling hindered by the lack of community for palliative care (though they could refer to hospice), which could be aided by a patient registry, a multidimensional needs assessment, decision aids, and support for care management to facilitate palliative care; coaches were helpful for some clinicians, and study participants noted that palliative care needs to be financially supported and prioritized by practices. Clinicians perceived that attention to the multidimensional domains of basic palliative care may enable clinical practices to address the unmet needs of patients

with complex illnesses by using existing practice improvement models, strategies, and prioritization.[92]

When. Perceptions of appropriate timing to implement shared decision-making models varied between patients and clinicians. In one study, patients stated a preference for the intervention to be provided after diagnosis,[80] yet another identified a preference for the beginning of the end of life.[82] From the clinician perspective, one study investigated willingness and perceived capacity to provide basic palliative care, also querying clinician concerns and perceived barriers; the authors concluded that palliative care should be provided to terminally ill patients or during preterminal stages to provide patient and family support.[92]

For Which Patients. These studies evaluated the implementation of models for integrating palliative care among patients with advanced heart failure,[80, 91] COPD,[81] and advanced renal disease[83] receiving ambulatory care, concluding that palliative care services should be provided for terminally ill and preterminal-stage patients to integrate patient and family support.[92]

In summary, models to integrate palliative care in ambulatory settings include a variety of components and have been implemented among patients with COPD,[81] end-stage renal disease,[83] and advanced heart failure.[80, 91] These models included communication strategies that facilitate shared decision-making,[80, 83] defined roles and responsibilities for each team member,[84] and structured workflows that promote easier integration.[84] These models were implemented by physicians, advanced practice nurses, social workers, or nurses in ambulatory settings. Although perceptions of the timing of effective implementation of models for integrating palliative care varied among patients and clinicians, no study reported perceptions that palliative care was implemented too early in the course of disease.

Integrative Review

Key Question 1. How can we identify those patients who could benefit from palliative care in ambulatory care settings, and what is the evidence for effectiveness and implementation of these methods?

Although a variety of potential prediction models, tools, and triggers are available as resources, none have been evaluated for effectiveness or implementation for integrating palliative care into ambulatory care. The effectiveness of triggers has been evaluated as part of multimodal interventions. Multimodal intervention studies have combined triggers with clinician training/education for primary care and advanced heart failure. Clinician/stakeholder Key Informants perceived that methods for patient identification and selection such as triggering/reminder systems are helpful, and that time and space to introduce palliative care in the ambulatory care setting is critical. Patient/caregiver Key Informants felt that palliative care options should be provided early and those options should be offered to all patients with serious illnesses.

Key Question 2. What educational resources are available for patients and caregivers in ambulatory care about integrating palliative care, and what is the evidence for their effectiveness and implementation?

Although a variety of relevant patient and caregiver education resources are available, none have been evaluated for effectiveness or implementation for integrating palliative care into ambulatory care. None of the multimodal or implementation studies included patient/caregiver educational resources. Patient/caregiver Key Informants perceived that clinicians should initiate discussions face-to-face and that clarifying the definition of palliative care is key. They also felt that this should be done in a patient-friendly, easily understandable manner and format, aided by educational materials.

Key Question 3. What palliative care shared decision-making tools for serious life-threatening chronic illness or conditions are available for clinicians, patients, and caregivers in ambulatory care, and what is the evidence for their effectiveness and implementation?

Shared decision-making tools relevant to integrating palliative care into ambulatory care all addressed the area of goals-of-care communication or advance care planning only. Palliative care shared decision-making tools may be effective for improving patient satisfaction with communication and advance directive documentation compared with control, but we were unable to draw conclusions about patient depressive symptom scores or caregiver satisfaction. In Table 24, we describe the integration of the implementation evidence with how these factors were included in implementation as part of effectiveness studies, but we were unable to determine evidence for specific factors in effectiveness. Qualitative evidence supported grounding in patient and caregiver experiences of illness, and this was a key component of several shared decision-making tools evaluated for effectiveness. Time constraints, resources, and integration into workflow were raised as concerns in implementation evidence, but all interventions that were evaluated involved additional personnel and resources.

Table 24. Overall integrative synthesis for shared decision-making tools based on adapted Consolidated Framework for Implementation Research[16]

Factors for Implementation of Shared Decision-Making Tools	Summary Findings
External factors	• None of the resources or studies addressed external factors; clinician/stakeholder Key Informants noted performance measures as a potential key factor.
Organizational factors	• Implementation studies noted concerns about implementation during routine care owing to time constraints; effectiveness studies were not conducted as part of routine care.
Organizational characteristics	• Effectiveness studies were conducted in both academic and community settings.
Collaboration, resources, and leadership	Collaboration • None of the resources, studies, or Key Informants addressed collaboration. Resources • All of the interventions evaluated for effectiveness involved additional personnel resources, including providing personalized feedback or trained peer mentors or nurses. Leadership None of the resources, studies, or Key Informants addressed leadership.
Intervention and implementation characteristics	Intervention • Content: Qualitative evidence supported grounding in patient and caregiver experiences of illness, and this was a key component of several shared decision-making tools evaluated for effectiveness. • Participants: Qualitative evidence from patients/caregivers supported acknowledging the caregiver's role and empowering and preparing them for open communication with patients. This was a key component of one of the interventions evaluated for effectiveness. • Structure: Although qualitative evidence supported that interventions should be time-efficient, specific, and succinct, effectiveness studies also included more lengthy interventions conducted by additional staff outside routine workflow. Implementation • Workflow: Although qualitative evidence supported integration into clinical workflow and standardized workflows, this was not generally how effectiveness studies were conducted. Timing: Although qualitative evidence from patients/caregivers supported individualizing timing to preferences, effectiveness studies provided interventions to all eligible patients or based on clinical triggers.
Clinician/team characteristics	• Qualitative evidence supported that advance care planning should be conducted by the clinician who knows the patient best; effectiveness studies were a mix of supporting primary clinicians and providing supplemental team members.
Patient/caregiver characteristics	• None of the resources, studies, or Key Informants addressed collaboration.

Key Question 4. What educational resources are available for nonpalliative care clinicians about integrating palliative care in ambulatory settings, and what is the evidence for their effectiveness and implementation?

A variety of clinician education and training resources for nonpalliative care clinicians are available for integrating palliative care into ambulatory care, but only one implementation study and two multimodal studies explicitly evaluated this component. Both clinician/stakeholders and patient/caregiver Key Informants expressed that more education and training is needed for

ambulatory care clinicians. Patient/caregiver Key Informants further perceived that clinician listening skills are especially important.

Key Question 5. What are the models for integrating palliative care into ambulatory settings, and what is the evidence for their effectiveness and implementation?

Models for integrating palliative care were not more effective than usual care for improving HRQOL, had little to no effect on reducing overall symptom burden, and were not effective for improving depressive symptom scores. The models had little to no effect on increasing patient satisfaction but did increase advance directive documentation. Four of the twelve studies about models for integrating palliative care evaluated a shared care model, four used a consultative model, and four used care coordinators or social workers in care. Multimodal interventions incorporating triggers and advance care planning had little to no effect on increasing advance directive documentation. Models for integrating palliative care have included shared care, consultative care, and care coordinator/social worker designs and a wide variety of components, characteristics, and implementation factors, and patients, caregivers, clinicians, and stakeholders perceive them as important (see Table 25); however, we were unable to draw specific conclusions about effects of types of models or specific components, characteristics, and implementation factors or multimodal interventions.

Clinician/stakeholder Key Informants had a number of suggestions for implementation, including integration into and simplification of workflows and documentation, leveraging delivery systems and payment mechanisms, documentation systems, connecting patients to community resources, interdisciplinary care, and integrating quality measurement and improvement. Patient/caregiver Key Informants perceived that clinicians should integrate palliative care into routine care, and that primary care is a key setting (see Table 26.

Table 25. Overall integrative synthesis for components and characteristics of models for integrating palliative care and multimodal interventions

Key Components and Characteristics of Delivery of Integrated Palliative Care	Summary Findings
Introducing palliative care	• Included in interventions as shared care consultative care and/or including care coordinators or social workers in care models. • Patient and clinician preferences for timing varied.
Communication	• Interventions ideally changed the way systems addressed serious illness communication. Key components include: • Addressing relationships • Facilitating better communication about difficult issues • Listening with compassion • Feeling heard
Addressing symptoms	• Focus on addressing unmet needs. • Symptom surveys should be focused, as often burdensome and repetitive.
Psychosocial care	• Involvement of interdisciplinary team care coordinators, including nurses and social workers, including psychosocial care, was key to many interventions.
Care planning	• Often best addressed by clinician who understands the context around their illness and its trajectory. Multimodal interventions used training of the patients' primary or specialty clinicians. • Clinician training is needed, as well as coaching, reminders, and maintenance.

Key Components and Characteristics of Delivery of Integrated Palliative Care	Summary Findings
Followup	• Interventions were generally longitudinal or included reminders. Key components included: • Linking to community resources • Ability to offer individualized solutions

Table 26. Overall integrative synthesis for implementation factors of models for integrating palliative care and multimodal interventions based on adapted Consolidated Framework for Implementation Research[16]

Factors for Implementation of Models for Integrating Palliative Care	Summary Findings
External factors	• Payment mechanisms and performance measures were perceived as important.
Organizational factors	• Minimizing patient burden was perceived as important to successful implementation.
Organizational characteristics	• Using existing practice improvement models, strategies, and prioritization was perceived as important to successful implementation.
Collaboration, resources, and leadership	<u>Collaboration</u> • Models should build on shared ownership and understanding of specific stakeholder needs. • Models benefit from attention to interprofessional relationships. <u>Resources</u> • Issues with models include clinician time, costs, and scheduling challenges. • We were unable to draw conclusions about effectiveness for costs and resource use for models, and multimodal interventions may have little or no effect. <u>Leadership</u> • Involvement can help align palliative care with local programs.
Intervention and implementation characteristics	<u>Intervention</u> • Clarifying goals was key, and low-burden interventions were perceived as easier to implement and preferred by patients. • A wide variety of characteristics were included in interventions, precluding specific conclusions. <u>Implementation</u> • Addressing stakeholder needs and relationships is key. • Clarify roles, responsibilities, and costs of interventions.
Clinician/team characteristics	• Nurses were particularly perceived as useful. • Clinician/team involvement in interventions varied and was often not specified, precluding specific conclusions. • Interdisciplinary care can be costly and is often not practical outside of funded grants.
Patient/caregiver characteristics	Not addressed

Discussion

Findings in Relation to the Decisional Dilemma

We used a mixed-methods review to address the key decisional dilemma for clinicians, patients, and family caregivers: "How can people with serious life-threatening chronic illness or conditions best receive ambulatory care that better integrates appropriate palliative care approaches?" To address this question, we sought to identify what was available, what was effective, and how to implement the following: resources to identify patients (prediction models, tools, and triggers) and guidelines and position statements, educational materials and resources for patients and caregivers, palliative care shared decision-making tools, palliative care training and educational materials for nonpalliative care clinicians, and models for integrating palliative care and multimodal interventions. We identified 46 Web resources, 20 quantitative effectiveness studies, and 16 qualitative implementation studies relevant to the integration of palliative care into ambulatory care for adults with serious life-threatening chronic illness or conditions other than cancer.

While Key Informants perceived that methods to identify patients are important, no resources on identifying patients for palliative care had evidence about effectiveness or implementation. No relevant patient/caregiver education and training materials had effectiveness or implementation evidence. Patient/caregiver Key Informants emphasized the importance of these materials and perceived that clinicians should initiate discussions face-to-face and that clarifying the definition of palliative care is key. Shared decision-making tools for serious illness or conditions all focused on advance care planning and advance directive (AD) documentation. We found that these tools may be effective for improving patient satisfaction (strength of evidence [SOE]: Low) and increasing AD documentation (SOE: Low); no studies addressed healthcare utilization, costs or resource use. For implementation, studies found that patients and caregivers preferred advance care planning discussions grounded in patient and caregiver experiences of illness, and that timing should be individualized to the specific patient and caregiver. Clinicians preferred tools that were time-efficient, structured, and integrated into workflows.

For nonpalliative care clinician training and educational materials, no studies evaluated effectiveness using objective or patient-centered measures. Both clinician/stakeholder and patient/caregiver Key Informants expressed that more education and training is needed for ambulatory care clinicians; patients/caregivers perceived that listening skills are especially important. The models evaluated for integrating palliative care into ambulatory care were not found to be effective for improving patient health-related quality of life (HRQOL) (SOE: Moderate), may have little to no effect on reducing patient symptom burden (SOE: Low), were not effective for improving depressive symptom scores, but were effective for increasing AD documentation (SOE: Moderate for both) compared with usual care. Patient perceptions of appropriate timing to initiate palliative care varied. No studies reported adverse effects or dropouts related to the interventions. For healthcare utilization, models for integrating palliative were not more effective than usual care for reducing hospitalizations; we were unable to draw conclusions about most other aspects of utilization or cost and resource use. Types of models (shared, consultative, and care coordinator/social worker) and components of interventions varied and interventions were often complex and included a variety of team members, making it difficult to draw conclusions about the effectiveness of specific intervention components.

Several existing systematic reviews of criteria for identification of potential palliative care referrals in outpatient oncology care, across settings and in the electronic medical record, also

found a wide variety of potential tools (including themes such as symptoms, diagnoses, prognosis, and performance status) with little evidence to support standard criteria or impact on patient outcomes.[4, 95, 96] For patient educational materials, although we did not identify studies on effectiveness, some evidence supports effectiveness of these types of approaches on increasing patient preferences for outpatient palliative care.[97]

Our review of shared decision-making tools focused on those evaluated in patients with serious illness and/or their caregivers. Systematic reviews of shared decision-making tools in broader populations, such as general primary care, have addressed effectiveness of decision aids and tools for advance care planning (ACP).[98, 99] Tools include ACP forms, patient and clinician educational materials, and Web- and video-based interventions. To date, these interventions have mainly demonstrated effectiveness for improving documentation about ACP and patient-surrogate congruence for preferences; evidence for improving patient/caregiver outcomes is limited. Studies of ADs in broader ambulatory care populations without serious illness have also shown good acceptability for implementation into practice.[100, 101] A systematic review of palliative care education for primary care physicians, mainly focusing on cancer care, showed some improvement in knowledge but little evidence for patient-centered outcomes.[102]

Other broader reviews of models for integrating palliative care have addressed populations with cancer and non-ambulatory settings, and included non-U.S.-based literature. One Australian-focused rapid review on elements of successful palliative care ambulatory generalist models defined these as "providing a framework or system for the organization of care for people with a progressive life-threatening illness and/or their family, carers or close friends."[7] Although our review was unable to identify factors associated with effective implementation in the United States, this review found that integrating palliative care specialist expertise with primary and other ambulatory care services was key to model success. Successful palliative care models addressed complexity of care and increasing patient comorbidity and longevity with serious illness and coordination with complex health systems and their interactions.[7] Similar to our review, a scoping review focusing on geriatric models across settings found that integrated palliative care focused mainly on symptoms and concerns, with key components of interdisciplinary and person-centered care and education.[103] As in our review, this review also found that economic analyses were poorly defined.[103]

Other recent systematic reviews of palliative care across settings have found evidence for small effects on the outcome of ACP and not for most other symptoms, as in our review, but did also find small effects on HRQOL and satisfaction.[104] Another review addressing key components associated with effective palliative care across settings found moderate-quality evidence for interdisciplinary care, but only low-quality evidence for early palliative care interventions.[1] A 2019 systematic review of integrated palliative care models in oncology only showed small benefits for short-term (but not long-term) HRQOL, and no effect for symptom burden, depressive symptom scores or healthcare utilization. The review also found insufficient data on intervention elements or integration to draw conclusions; half of the studies included a telephone component.[3] A 2016 systematic review of the effect of a wide variety of palliative care interventions on economic outcomes found no evidence for beneficial effects.[105]

Strengths and Limitations

The evidence for better integration of palliative care into ambulatory care for adults with serious life-threatening chronic illness or conditions included studies of a wide variety of interventions, illnesses and settings, and outcomes. Although many proposed prediction models, tools, and triggers exist, studies of triggers generally only address their accuracy for prediction, rather than their implementation or their effect on patient or caregiver outcomes. One implementation study and two effectiveness studies did include triggers as a key part of the multimodal intervention. Patients with certain characteristics can 'trigger' a prompt or action, which then may lead to an intervention, which may or may not be accepted, which may lead to an improved outcome. Failure can occur at any step along this causal pathway. The number of studies on shared decision-making tools was relatively small, as most existing literature does not address serious illness populations or evaluate patient and caregiver outcomes. All shared decision-making tools addressed goals-of-care communication and ACP and no other palliative care domains, such as symptom management.

We identified only one study of clinician education assessing implementation; published effectiveness studies of clinician education did not include objective measures, such as knowledge or patient-centered outcomes, but only subjective clinician outcomes, such as self-reported confidence or satisfaction. The lack of strong evidence assessing models for integrating palliative care reflects the literature, which often lacks controlled designs and evaluates only model processes and not patient or caregiver outcomes. We did not identify any mixed-methods or process evaluation studies or studies comparing implementation using different strategies or settings.

Studies included in our review had a variety of limitations, including lack of standard information on details of the interventions and how and how well they were implemented or addressed contextual issues, making comparisons across studies challenging. Outcomes were measured using a variety of assessment tools, many of which are not validated for palliative care populations. Owing to missing information and variation in outcomes measured, we were able to conduct only a few meta-analyses. Furthermore, most of the quantitative studies were at high risk of bias and qualitative studies often lacked rigorous reporting or methods. Adverse effects and burden and costs to patients and caregivers were not reported in any studies. Dropouts were generally not characterized as to whether they were related to the intervention or its burdens. Outcomes of shared decision-making tools were often short-term. Long-term sustainability/implementation issues were not evaluated, which is particularly important as all interventions were supported by external funding and required significant additional resources. Although most common serious chronic conditions, such as advanced heart failure, chronic obstructive pulmonary disease (COPD), and end-stage renal disease (ESRD) were represented in at least some Web resources and studies, few Web resources and none of the studies addressed the important ambulatory palliative care issues of multimorbidity or frailty. We identified little relevant information on education, for patients and caregivers or for clinicians.

Our review also had several limitations. Our Web resources search was limited to information posted on websites and resources clearly focused on integrating palliative care into ambulatory care. The search was also limited to key U.S. national palliative care, health professional, and consumer organizations information posted on the Web; and it did not include the wide variety of resources available through many health systems, individual states, and other private organizations. Although we focused on shared decision-making tools evaluated in serious chronic illness populations, tools evaluated for broader populations may be appropriate and

relevant and, thus, much of this evidence may also be applicable. Since models for other countries' health systems are often not translatable to the U.S. context, we did not include these in our review, although some findings may be applicable to the U.S. context. We used accepted standards for clinically meaningful differences, but these were not all from palliative care populations and some might consider these smaller differences meaningful.

Applicability

The evidence did not support specific conclusions for patients with specific illnesses; the studies of both shared decision-making tools and models most commonly included ESRD, COPD, and heart failure populations. However, the conclusions may be applicable to other patients with serious illness. Studies of shared decision-making tools addressed only goals-of-care communication and ACP and did not address other domains of palliative care, including symptom management. These studies also focused on in-person, often resource-intensive interventions. Trials of different methods of incorporating shared decision-making tools into ambulatory care for serious illness, such as patient-self management and Web and electronic health record portal interventions, are ongoing.[106, 107]

Models used shared care, consultative care, or the incorporation of care coordinators or social workers into care as methods of integration. Many interventions were evaluated only in academic settings, and results may not be translatable to community settings. All studies had external funding; it may not be financially practical to translate results into actual clinical practice using the same intensity of intervention. Finally, none of the studies of models or multimodal interventions, and few of the studies about shared decision-making tools, included the caregiver perspective or outcomes, which is critical in the provision of palliative care for patients with serious illness.

Implications for Clinical Practice, Education, Research, or Health Policy

In terms of clinical practice and health policy, this systematic review found evidence of acceptability to patients, caregivers, and clinicians for both shared decision-making tools and models to integrate palliative care approaches. These have been successfully implemented into a variety of ambulatory care settings and have some evidence for effectiveness in a variety of settings and populations. Shared decision-making tool interventions addressed both goals-of-care communication and ACP and included approaches to facilitate interventions by patients' usual clinicians and those involving interventionists or peers; interventions generally focused on patients' broader preferences, goals and values, and communication, rather than specific end-of-life decisions. Models that focused on approaches of shared care and the incorporation of care coordinators or social workers into practice and interdisciplinary care, particularly with nurses, was a key factor.

In terms of future research, for shared decision-making tools, more research is needed beyond one-time ACP and outcomes beyond ADs completion, and for broader serious illness communication and symptom management. For models for integrating palliative care, more research is needed on combined approaches with different options for patients, where different options and their timing can be tailored to patient and caregiver circumstances and preferences. These patients have many symptoms, needs, and concerns and often have multiple chronic illnesses that affect their care and HRQOL; studies should address palliative care that addresses

these complex issues, and overall symptom burden should be included as an important outcome. Interventions were often complex and multifaceted but did not evaluate the potential impact of specific components; research addressing this issue might help lead to interventions that are targeted and potentially less burdensome, less costly, and easier to implement in real-life, busy ambulatory practice workflow. Most studies had major methodologic limitations; the quality of the evidence and ability to synthesize study results would be improved by following established criteria for high-quality palliative care clinical trials, including clear descriptions of intervention components and the fidelity and quality of delivery, recruitment and retention, and choice of outcomes validated for palliative care, outcome measurement, and analysis.[108-110]
A major challenge of the palliative care interventions literature continues to be the wide variety of outcomes measured in studies and frequent use of a variety of measurement instruments or reporting, making synthesis and conclusions difficult. Similarly, qualitative implementation studies should follow established criteria for quality qualitative research.[14, 111] Measuring cost and resource use, both of the intervention itself and as an outcome, is critical and future studies should follow established best practices for economic evaluations, generally, and palliative care, specifically.[111, 112] The cost and burden to patients and caregivers and other adverse effects, such as medication side effects, are critical issues for patients but were not included in any of these studies and should be addressed in future studies, as well. Studies of specific serious illnesses may not be relevant to populations with frailty or multimorbidity, and these groups should be included or focused on in future research, particular given the growing needs of the aging U.S. population. None of these studies specifically addressed health equity or disparities as part of the intervention, which are critical to patient-provider care in ambulatory settings and future cultural appropriate intervention research.

In terms of answering the decisional dilemma and implications for the Agency for Healthcare Research and Quality Learning Health Systems Panel, these interventions mainly add additional staff or processes to existing systems of care with little to no impact on outcomes. These patients often have intense, varying and complex care needs and are treated across settings and in the community. Developing and implementing rigorous studies or systems of care that work for this population is challenging. As noted in the recent National Academies of Medicine Report, *Dying in America*, and subsequent discussion papers and workshops, improving care for those with serious, life-threatening illness and conditions requires comprehensive, individualized, often time-consuming care and systems oriented towards their needs and coordination with community services.[113, 114] For clinician-patient communication about palliative care, given that frequent and often detailed conversations about the end of life are needed, the *Dying in America* report recommends better systems support and infrastructure for improved communication skills and the time for these conversations, which generally require involvement from nonpalliative care clinicians. For policy, the report recommends that the healthcare system and payment structures need to also support other important domains in palliative care, including symptom management and care coordination, and improve home support and social services and their integration with medical care. The interventions we identified address aspects more relevant to clinicians, such as advance directives and prescribing medications for symptoms, rather than those that may matter more to patients and caregivers, such as function, coordination of care, and caregiving needs.[114] In addition, other research has found that little evidence exists on effective interventions for common symptoms in palliative care, and ongoing research and drug development are sparse; advances in the science of symptom management in these populations are needed for interventions evaluating models to impact these outcomes.[115]

For U.S. health policy, as U.S. healthcare is currently moving to less visit-based models, with changes from the proposed Centers for Medicare and Medicaid Innovation Primary Care First and Serious Illness Population models and changes in care accelerated by the COVID-19 pandemic, models for integrating palliative care may become of increased importance and ongoing evaluations of telehealth for care delivery will be particularly valuable. These results on the effectiveness of successful integration could also have implications for earlier provision of palliative care services for patients with serious illness, including initiatives by the Centers for Medicare and Medicaid Innovation and private insurers, which could be more effective and efficient with better integration into ongoing ambulatory care for these patients. Other methods for improving the efficiency of palliative care integration could include linking palliative care triggers to approaches in growing use by payors and systems to identify patients with or at high risk for healthcare utilization for care management.

Conclusions

For better integration of palliative care into ambulatory care for serious life-threatening chronic illness or conditions other than cancer, ACP shared decision-making tools may increase patient satisfaction and AD documentation. The models evaluated for integrating palliative care were not effective for improving HRQOL and had little to no effect on reducing overall symptom burden and were not effective for improving depressive symptom scores, but were effective for increasing AD documentation. Further research is particularly needed on identification of patients; educational materials for patients, caregivers, and clinicians; shared decision-making tools beyond ACP and AD completion; specific components, characteristics, and implementation factors in models to integrate palliative care into ambulatory care; and when and how to integrate palliative care among those with frailty and/or multimorbidity. Further research also needs to consider the real-life and most important concerns of those impacted by serious illness and conditions. Fundamental changes in the healthcare system and advances in the science of palliative care are needed to improve palliative care approaches in ambulatory care to better improve patient- and caregiver-centered outcomes.

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Abbreviations

AAICP = Advanced illness coordinated care program
ACP = Advance care planning
AD = Advance directive
AHRQ = Agency for Healthcare Research and Quality
ANOVA = Analysis of variance
APNs = Advanced Practice Nurses
CASA = Collaborative care to alleviate symptoms and adjust to illness
CHF = Congestive heart failure
CI = Confidence interval
CCT = Comprehensive care team
CINAHL=Cumulative Index of Nursing and Allied Health Literature
COPD = Chronic obstructive pulmonary disease
COVID-19 = Coronavirus disease 2019
CT = Controlled trial
DPOA-HC = Durable Power of Attorney for Health Care
ED = Emergency department
ESAS = Edmonton Symptom Assessment Scale
EPC = Evidence-based Practice Center
ESRD = End stage renal disease
FACIT-PAL = Functional Assessment of Chronic Illness Therapy – Palliative Care scale
GAD-7 = Generalized Anxiety Disorder scale 7-item
GOLD = Global Initiative for Chronic Obstructive Lung Disease
HADS = Hospital Anxiety and Depression Scale
HRQOL = Health-related quality of life
ICD-10 = International Classification of Diseases, tenth revision
ICU = Intensive care unit
IQR = Interquartile range
KCCQ = Kansas City Cardiomyopathy Questionnaire
KIs = Key Informants
KQ = Key Question
LACE = Length of stay, acuity of admission, comorbidities, emergency department visits
LVAD = Left Ventricular Assist Devices
NA = Not available
NR = Not reported
NYHA = New York Heart Association
PCDM = Patient-centered disease management
PCMH = Patient-centered medical home
PEG = Pain intensity, enjoyment of life, general activity
PHQ-9 = Patient Health Questionnaire 9-item
PHQ-8 = Patient Health Questionnaire 8-item
POLST = Provider Orders for Life-Sustaining Treatment
PRISMA = Preferred Items for Reporting in Systematic Reviews and Meta-Analyses
RCT = Randomized clinical trial
ROBINS-I tool = Risk of Bias Assessment Tool for Non-Randomized Studies of Interventions
RR = Relative risk

SD = Standard deviation
SDM-RSC = Shared Decision-Making and Renal Supportive Care
SE = Standard error
SMD = Standardized mean difference
SOE = Strength of evidence
SPICT = Supportive and palliative care indicators tool
SPIRIT = Sharing Patients' Illness Representation to Increase Trust
TEP = Technical Expert Panel
VA = Veterans Affairs

Appendix A. Methods

Details of Study Selection

Search Strategy

Part (a)

We searched key websites from health care professional organizations relevant to primary care, including specialties and palliative care, and other established relevant Federal government and national U.S. nonprofit and patient organization Web resources in March 2020 (Table A-1). We limited the search to resources that had been developed or updated within the last 5 years given significant changes in evidence and guidelines in ambulatory palliative care.

Part (b)

We searched the following databases for quantitative studies: PubMed, CINAHL, and the Cochrane Central Register of Controlled Trials January 2000 to May 20, 2020 (the year 2000 is the start of the palliative care movement in the U.S. and ambulatory palliative care programs were not available before that year). We developed a search strategy for PubMed, based on an analysis of the medical subject headings (MeSH) terms and text words of key articles identified a priori.

We hand searched the reference lists of included articles and relevant systematic reviews. We looked for relevant studies during our search of websites (part a).

Part (c)

As part of the searches for part (b), we also searched for qualitative, mixed methods and process evaluation studies. We also modified the search strategy from Part (b) to search for systematic reviews of qualitative studies.

Table A-1. Websites searched

Organization Specialty	Organization Name
Key palliative care organizations	National Coalition for Hospice and Palliative Care (NCHPC) www.nationalcoaltionhpc.org
	Center to Advance Palliative Care (CAPC) www.capc.org/getpalliativecare.org
	Hospice and Palliative Nurses Association www.advancingexpertcare.org
	American Academy of Hospice and Palliative Medicine (AAHPM) aahpm.org/
	Social Work Hospice & Palliative Care Network (SWHPN) www.swhpn.org
	Council on Social Work Education (CSWE) www.cswe.org
	Physician Assistants in Hospice and Palliative Medicine (PAPHM) www.pahpm.org
	Society of Pain and Palliative Care Pharmacists (SPPCP) www.palliativepharmacist.org
	National Hospice and Palliative Care Organization www.nhpco.org/education
	National Consensus Project for Quality Palliative Care www.nationalcoalitionhpc.org/ncp
Key primary care health care professional organizations	American College of Physicians www.acponline.org
	Society of General Internal Medicine www.sgim.org
	American Academy of Family Physicians www.aafp.org/home.html
	Key specialty health care professional organizations
	American Geriatrics Society www.americangeriatrics.org
	American College of Cardiology https://www.acc.org
	American Thoracic Society www.thoracic.org
	American Society of Nephrology www.asn-online.org
	American Nurses Association https://www.nursingworld.org
	American Nurses Foundation www.nursingworld.org/foundation
	Gerontological Advanced Practice Nurses Association www.gapna.org
	National Association of Social Workers (NASW) www.socialworkers.org
Widely used curricula	End-of-Life Nursing Education Consortium (ELNEC) www.aacnnursing.org/ELNEC
	EPEC: Education in Palliative & End of Life Care www.bioethics.northwestern.edu/programs/epec/about/index.html

Organization Specialty	Organization Name
Key U.S. Federal Government organizations	National Institute of Nursing Research (NINR) www.ninr.nih.gov
	National Institute on Aging www.nia.nih.gov
	Health Resources and Services Administration www.hrsa.gov
	Center for Medicare and Medicaid Services www.cms.gov
	National Academy of Science Roundtable on Quality of Care for People with Serious Illness https://www.nationalacademies.org/our-work/roundtable-on-quality-care-for-people-with-serious-illness
Key national U.S. foundations with major focus in palliative care	
	John A. Hartford Foundation www.johnahartford.org
	Cambia Health Foundation Cambiahealthfoundation.org
	Gordon and Betty Moore Foundation www.moore.org
	Pew Charitable Trusts www.pewtrusts.org/en
	Henry J. Kaiser Family Foundation https://www.kff.org
Key patient organizations	
	Alzheimer's Association www.alz.org
	American Heart Association www.heart.org
	American Lung Association www.lung.org
	National Kidney Foundation www.kidney.org
	Coalition for Supportive Care of Kidney Patients https://www.kidneysupportivecare.org/
	Amerian Association of Retired Persons (AARP) www.aarp.org
	National Alliance for Caregiving www.caregiving.org

Literature Search Strategies

PubMed

Table A-2. Lead search string—population

Search #	Search String
1	"palliative care"[mh]
2	"palliative care"[tiab]
3	"serious illness"[tiab]
4	"supportive care"[tiab]
5	"Advance Care Planning"[Mesh]
6	"Advance Care Planning"[tiab]
A	1 OR 2 OR 3 OR 4 OR 5 OR 6
7	"Ambulatory Care"[Mesh]
8	"Primary Health Care"[Mesh]
9	"ambulatory care"[tiab]
10	"primary care"
11	Outpatient[tiab]
12	Ambulatory[tiab]
B	7 OR 8 OR 9 OR 10 OR 12
	A AND B
	English language
	Not Review

Table A-3. KQ1 (5 August addition of targeted "predictive model" terms)

Search #	Search String
1	Population string (see above)
2	Tool[tiab]
3	Tools[tiab]
4	"trigger"[tiab]
5	"model of care"
6	"models of care"[tiab]
7	2 OR 3 OR 4 OR 5 OR 6
8	Model[tiab]
9	Models[tiab]
10	8 OR 9
11	predictive[tiab]
12	prediction[tiab]
13	predict[tiab]
14	identity[tiab]
15	identification[tiab]
16	11 OR 12 OR 13 OR 14 OR 15
17	10 AND 16
18	7 OR 17
17	1 AND 18
	Date limited (2000 to present)
	Not review
	English Language

Table A-4. KQ2 and KQ4

Search #	Search String
1	Population string (see above)
2	"Education"[Mesh]
3	education[tiab]
4	educational[tiab]
4a	Strategy[tiab]
4b	Training[tiab]
4c	Teaching[tiab]
4d	Curriculum[tiab]
5	1 OR 2 OR 3 OR 4 OR 4a OR 4b OR 4c OR 4d
6	1 AND 5
	Date limited (2000 to present)
	Not review
	English Language

Table A-5. KQ3

Search #	Search String
1	Population string (see above)
2	"Decision Making"[Mesh]
3	"shared decision making"[tiab]
4	“decision support”[tiab]
4a	“goals of care”[tiab]
4b	“advanced care planning”[tiab]
5	2 OR 3 OR 4
6	1 AND 5
	Date limited (2000 to present)
	Not review
	English Language

Table A-6. KQ5

Search #	Search String
1	Population string (see above)
2	coaching[tiab]
3	integrating[tiab]
4	"stepped care"[tiab]
5	"consultative care"[tiab]
6	"shared care"[tiab]
7	"Collaborative care"[tiab]
8	2 OR 3 OR 4 OR 5 OR 6 OR 7
9	Model[tiab]
10	Models[tiab]
11	9 OR 10
12	"chronic care"[tiab]
13	staffing[tiab]
14	Dignity[tiab]
15	"needs based"[tiab]
16	"clinical practice"[tiab]
17	"primary care"[tiab]
18	integrated[tiab]
19	12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18
20	11 and 19
21	8 OR 20
22	1 and 21
	Date limited (2000 to present)
	Not review
	English Language

CINAHL

Table A-7. CINAHL

Search Terms	Search Options
S18	S16 AND S17
S17	S1 AND S2
S16	S3 OR S8 OR S9 OR S10 OR S15
S15	S11 OR S14
S14	S12 AND S13
S13	TI ("chronic care" OR staffing OR dignity OR "needs based" OR "clinical practice" OR "primary care" OR integrated) OR AB ("chronic care" OR staffing OR dignity OR "needs based" OR "clinical practice" OR "primary care" OR integrated)
S12	TI (model OR models) OR AB (model OR models)
S11	TI (coaching OR integrating OR "stepped care" OR "consultative care" OR "shared care" OR "collaborative care") OR AB (coaching OR integrating OR "stepped care" OR "consultative care" OR "shared care" OR "collaborative care")
S10	MH "decision making" OR TI ("decision making" OR "decision support" OR "goals of care" OR "advance care planning") OR AB ("decision making" OR "decision support" OR "goals of care" OR "advance care planning")
S9	MH (education OR curriculum OR teaching) OR TI (education OR educational OR strategy OR training OR teaching OR curriculum) OR AB (education OR educational OR strategy OR training OR teaching OR curriculum)
S8	S4 OR S7
S7	S5 AND S6
S6	TI (predictive OR prediction OR predict OR identity OR identification) OR AB (predictive OR prediction OR predict OR identity OR identification)
S5	TI (model OR models) OR AB (model OR models)
S4	(tool OR tools OR trigger OR "model of care" OR "models of care") OR (tool OR tools OR trigger OR "model of care" OR "models of care")
S3	(MH "ambulatory care" OR "primary health care" OR outpatients" OR TI "ambulatory care" OR "primary care" OR outpatient" OR ambulatory OR AB "ambulatory care" OR "primary care" OR outpatient" OR ambulatory) AND (S1 AND S2)
S2	MH ("ambulatory care" OR "primary health care" OR outpatients") OR TI ("ambulatory care" OR "primary care" OR outpatient" OR ambulatory) OR AB ("ambulatory care" OR "primary care" OR outpatient" OR ambulatory)
S1	MH ("Palliative care" OR "advance care planning") OR TI ("palliative care" OR "serious illness" OR "supportive care" OR "Advance care planning") OR AB ("palliative care" OR "serious illness" OR "supportive care" OR "Advance care planning")

Cochrane Central Register of Controlled Trials

Table A-8. Cochrane Central Register of Controlled Trials

ID	Search
#1	MeSH descriptor: [Palliative Care] explode all trees
#2	MeSH descriptor: [Advance Care Planning] explode all trees
#3	("palliative care"):ti,ab,kw (Word variations have been searched)
#4	("serious illness"):ti,ab,kw (Word variations have been searched)
#5	("supportive care"):ti,ab,kw (Word variations have been searched)
#6	("advance care planning"):ti,ab,kw (Word variations have been searched)
#7	#1 OR #2 OR #3 OR #4 OR #5 OR #6
#8	MeSH descriptor: [undefined] explode all trees
#9	MeSH descriptor: [Primary Health Care] explode all trees
#10	("ambulatory care"):ti,ab,kw (Word variations have been searched)
#11	("primary care"):ti,ab,kw (Word variations have been searched)
#12	(outpatient):ti,ab,kw (Word variations have been searched)
#13	#8 OR #9 OR #10 OR #11 OR #12
#14	#7 AND #13
#15	(tool):ti,ab,kw (Word variations have been searched)
#16	(tools):ti,ab,kw (Word variations have been searched)
#17	(trigger):ti,ab,kw (Word variations have been searched)
#18	("model of care"):ti,ab,kw (Word variations have been searched)
#19	("models of care"):ti,ab,kw (Word variations have been searched)
#20	#15 OR #16 OR #17 OR #18 OR #19
#21	(model):ti,ab,kw (Word variations have been searched)
#22	(models):ti,ab,kw (Word variations have been searched)
#23	#12 OR #22
#24	(predictive):ti,ab,kw (Word variations have been searched)
#25	(prediction):ti,ab,kw (Word variations have been searched)
#25	(predict):ti,ab,kw (Word variations have been searched)
#27	(identity):ti,ab,kw (Word variations have been searched)
#28	#28 (identification):ti,ab,kw (Word variations have been searched)
#29	#24 OR #25 OR #26 OR #27 OR #28
#30	#23 AND #29
#31	#20 OR #30
#32	MeSH descriptor: [Education] explode all trees
#33	(education):ti,ab,kw (Word variations have been searched)
#34	(educational):ti,ab,kw (Word variations have been searched)
#35	(strategy):ti,ab,kw (Word variations have been searched)
#36	(training):ti,ab,kw (Word variations have been searched)
#36	(teaching):ti,ab,kw (Word variations have been searched)
#38	(curriculum):ti,ab,kw (Word variations have been searched)
#39	#32 OR #33 OR #34 OR #35 OR #36 OR #37 OR #38
#40	MeSH descriptor: [Decision Making] explode all trees
#41	("shared decision making"):ti,ab,kw (Word variations have been searched)
#42	("decision support"):ti,ab,kw (Word variations have been searched)
#43	("goals of care"):ti,ab,kw (Word variations have been searched)
#44	#40 OR #41 OR #42 OR #43
#45	(coaching):ti,ab,kw (Word variations have been searched)
#46	(integrating):ti,ab,kw (Word variations have been searched)
#47	("stepped care"):ti,ab,kw (Word variations have been searched)
#48	("consultative care"):ti,ab,kw (Word variations have been searched)
#49	("shared care"):ti,ab,kw (Word variations have been searched)
#50	("collaborative care"):ti,ab,kw (Word variations have been searched)
#51	#45 OR #46 OR #47 OR #48 OR #49 OR #50
#52	(MODEL):ti,ab,kw (Word variations have been searched)
#53	(models):ti,ab,kw (Word variations have been searched)
#54	#52 OR #53

#55	("chronic care"):ti,ab,kw (Word variations have been searched)
#56	(staffing):ti,ab,kw (Word variations have been searched)
#58	(dignity):ti,ab,kw (Word variations have been searched)
#59	("needs based"):ti,ab,kw (Word variations have been searched)
#60	("Clinical practice"):ti,ab,kw (Word variations have been searched)
#61	("primary care"):ti,ab,kw (Word variations have been searched)
#62	(integrated):ti,ab,kw (Word variations have been searched)
#63	#55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61
#64	#54 AND #62
#65	#51 OR #63
#66	#31 OR #39 OR #44 OR #64

We used DistillerSR (Evidence Partners, 2020), a Web-based database management program, to manage the screening process for studies.[1] All citations identified by the search strategies were uploaded to the system and reviewed in the following manner:

Abstract screening: Two reviewers independently reviewed abstracts. Abstracts were excluded if both reviewers agreed that the article met one or more of the exclusion criteria (Table A-8). Differences between reviewers regarding abstract eligibility were tracked and resolved through consensus adjudication. Relevant reviews, including systematic reviews and meta-analyses, were tagged for a references list search.

Full-text screening: Citations promoted based on abstract review underwent another independent parallel review using the full-text of the articles. Any differences regarding article inclusion were tracked and resolved through consensus adjudication.

Inclusion and Exclusion Criteria

Part (a)

Criteria for inclusion and exclusion of Web resources are based on the Key Questions and are briefly described in Tables A-9 and A-10 (eligible Web resources had to meet all criteria, be from one of the key national US websites as in the search strategy and Table A-1, and have specific relevance to the integration of palliative care into ambulatory care for non-cancer serious chronic illness or conditions). We reviewed U.S. key national websites to which we had either free access or memberships, and based inclusion on available descriptions of materials on the websites.

Table A-8. Specific inclusion criteria for web resources

Type	Criteria
Content	Relevant to any of the interventions
Language/Country	English/United States
Admissible evidence	Web resource developed or updated in past 5 years.

Part (b)

The eligible studies had to meet all of the following criteria: (1) included adults 18 years of age and older with serious life threatening chronic illness or conditions (other than those only with cancer) and their caregivers, being seen in ambulatory settings; (2) included prediction models, tools, or triggers to identify patients for palliative care in ambulatory settings (KQ1); (3) included educational materials and resources for patients and/or caregivers about palliative care in ambulatory settings (KQ2); (4) included palliative care shared decision-making tools and resources for clinicians and patients and/or caregivers in ambulatory settings (KQ3); (5) included palliative care training or educational materials for ambulatory settings (KQ4); (6) included models for integrating palliative care or multimodal interventions in ambulatory settings (KQ5); (7) reported outcomes of interest; (8) randomized controlled trial or non-randomized trial with a concurrent or historical comparison group (controlled trial or prospective cohort study) (all KQ part b, effectivess questions); (9) published in English; and, (10) U.S.-based.
The criterion for outcomes was applied at the full-text screening level only. An overview of the PICOTS inclusion and exclusion criteria is provided in Table 3.

Part (c)

The criteria for inclusion and exclusion of qualitative, mixed-methods and process evaluation studies were based on the Key Questions and are described in Table A-10.

Table A-9. PICOTS: Inclusion and exclusion criteria for quantitative studies

Type	Inclusion	Exclusion
Population	Patients (≥18 years of age) with serious life-threatening chronic illness or conditions (other than those only with cancer) and their caregivers, being seen in ambulatory settings (KQs 1,2,3,5) Clinicians practicing in ambulatory settings (KQ4)	Studies with only cancer patients Studies not focusing on ambulatory populations Studies of clinicians caring only for cancer patients Studies focusing on trainees
Interventions	KQ1: prediction models, tools, or triggers to identify patients for palliative care in ambulatory settings KQ2: educational materials and resources about palliative care for patients and/or caregivers in ambulatory settings KQ3: palliative care shared decision-making tools and resources for clinicians and patients and/or caregivers in ambulatory settings KQ4: palliative care training or educational materials for ambulatory settings KQ5: models for integrating palliative care or multimodal interventions in ambulatory settings	Studies that report no intervention of interest
Comparisons	KQ1: prediction models, tools, or triggers to identify patients for palliative care in ambulatory settings KQ2: educational materials and resources about palliative care for patients and/or caregivers in ambulatory settings KQ3: palliative care shared decision-making tools and resources for clinicians and patients and/or caregivers in ambulatory settings KQ4: palliative care training or educational materials for ambulatory settings KQ5: models for integrating palliative care or multimodal interventions in ambulatory settings Usual care for all KQs	Studies that do not report the comparisons of interest

Type	Inclusion	Exclusion
Outcomes	Intermediate Knowledge (clinicians, patients, caregivers) (KQ2, KQ4) Awareness (clinicians, patients, caregivers) (KQ2, KQ4) Skills (clinicians) (KQ4) Final (All apply to all KQ) (In hierarchy from patient-centered to clinician to health system. All patient or caregiver-reported outcomes must be measured by a validated instrument.[2]) Patient or caregiver satisfaction Patient or caregiver health-related quality of life Patient or caregiver symptoms of depression, anxiety, or psychological well-being Caregiver burden, caregiver impact, or caregiver strain Patient symptoms or symptom burden (includes multidimensional symptom tools and key symptoms of pain, dyspnea, fatigue); this must include patient-reported symptom measurement (or caregiver-reported for patients unable to report) Concordance between patient preferences for care and care received Clinician job satisfaction or burnout, perceptions of teamwork Healthcare utilization (use and length of hospice care, hospitalizations, advance directive documentation) and costs and resource use (use of outpatient clinician services, including palliative care) Adverse effects Medication side effects Dropouts	Studies that do not report the outcomes of interest Excludes clinician self-report for intermediate outcomes
Type of Study	Randomized controlled trials Non-randomized studies with concurrent or historical controls	Articles published prior to the year 2000 Non-English publications Case reports or case series Publications with no original data (e.g., editorials, letters, comments, reviews) Full text not presented or unavailable, abstracts only
Timing and Setting	Any timing Ambulatory care settings U.S.-based studies	Hospital setting Oncology setting Emergency department Nursing home and long-term care facilities

Table A-10. Specific inclusion and exclusion criteria for qualitative, mixed-methods and process evaluation studies

Criteria	Inclusion	Exclusion
Comparison	No comparison group needed	
Type of study	Systematic reviews of qualitative studies Qualitative or mixed-methods studies: include studies that use a formal qualitative data collection method (e.g., interviews, focus groups, or ethnography) and analysis methods (e.g., phenomenological, grounded theory, ethnographic and thematic analysis studies) Process evaluation studies (type of implementation studies) including studies that address in results: Identifying/addressing barriers/facilitators Populations to target Mechanisms for success/failure	Qualitative studies: observation or artifact analysis Process evaluation studies focusing only on research issues (e.g., fidelity, participant recruitment, intervention quality, participant engagement)
Sample size		Analysis of interest includes fewer than 10 participants

Table A-11. Minimal clinically important differences and clinical cutoff scores for outcome assessment tools included in review

Domain/ Instrument	Scale	Minimal Clinically Important Differences (MCIDs)	Clinical Cutoff Scores
Patient Satisfaction			
Group Health Association of America Consumer Satisfaction Survey	20 - 100	None identified	None identified
Investigator constructed 5-point, Likert type scale	0 - 5	None identified	None identified
Health-Related Quality of Life			
Kansas City Cardiomyopathy Questionnaire (KCCQ)[3, 4]	0 -100	4.3 (95%, CI 0.2 – 8.4)	
		5.3 (+/- 11) (deterioration) 5.7 (+/- 16) (improvement)	
McGill Quality of Life Questionnaire[4]	0 - 10	None identified	Good 7.9 (SD 1.3) Average (6.8 SD 1.2) Bad 5.3 (SD 1.1)
Multidimensional Quality of Life Scale – Cancer Version[5]	0 - 10	None identified	Low 8.7 (SD 0.8) High 6.6 (SD 1.2)
Functional Assessment of Chronic Illness Therapy – Palliative Care scale (FACIT-PAL)[6]	0-184	None identified	Karnofsky Performance ≤ 70 (cancer patients less able to carry out daily activities): 125.3 (SD 25.2)

Domain/ Instrument	Scale	Minimal Clinically Important Differences (MCIDs)	Clinical Cutoff Scores
			Karnofsky Performance ≥80 (cancer patients more able to carry out daily activities): 134.3 (SD 24)
Minnesota Living with HF Questionnaire (MLHFQ)[7]	0 - 105	19.14 (95% CI16.04 – 22.24)	
Quality of Life in Alzheimer's Disease (QoL-AD)[8, 9]	13 - 52	3.9	
		Half a standard deviation	
Bakas Caregiving Outcomes Scale	15 - 105	None identified	
Overall Symptom Burden			
General Symptom Distress Scale	0 - 10	None identified	
Edmonton Symptom Assessment Scale – Revised for Parkinson's Disease (ESAS – PD)	0 -140	None identified	
Depression			
Patient Health Questionnaire – 8 (PHQ8)[10]	0-24	None identified	≥ 10 represents clinically significant depression
Patient Health Questionnaire – 9 (PHQ9)[11, 12]	0 - 27	5	
Edmonton Symptom Assessment Scale (ESAS)[13, 14]	0 -10	(improvement and deterioration)	
		1 Range: 0.8 to 2.2 (improvement) -0.8 to -2.3 (deterioration)	
Center for Epidemiological Studies Depression Scale[15-17]	0-60		Optimal cutoff score of 4
		There is no MCID for CESD	
		0.9	
Hospital Anxiety and Depression Scale (HADS)[18-20]	0 - 21	1.7 (Range 0.5 – 5.57)	
		1.6 (95% CI, 1.38 – 1.82) to 1.68 (95% CI, 1.48 – 1.87)	
		1.4 – 1.8	
Anxiety			
Generalized Anxiety Disorder – 7 (GAD-7)[21, 22]	0 - 21	3	
		4	
Edmonton Symptom Assessment Scale (ESAS)[13, 14]	0 - 10	1.1 (deterioration)	
		1	

Domain/ Instrument	Scale	Minimal Clinically Important Differences (MCIDs)	Clinical Cutoff Scores
Profile of Mood States (POMS)	0-200	None identified	None identified
Hospital Anxiety and Depression Scale (HADS)[18-20]	0 - 21	1.7 (Range 0.81 – 5.21)	
		1.41 (95% CI, 1.18 – 1.63) to 1.57 (95% CI, 1.37 – 1.76)	
		1.1 - 2	
Psychological Well-Being			
Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being Scale (FACIT Sp-12)[23]	0 - 48	No reported MCID	
Spiritual Well-Being Scale	20 - 120	None identified	None identified
Pain			
Composite from the Brief Pain Inventory called PEG: pain intensity (P), interference with enjoyment of life (E) and interference with general activity (G)		None identified	None identified
Edmonton Symptom Assessment Scale (ESAS)[13, 14]	0 - 10	1.2 (improvement) 1.4 (deterioration)	
		1	
Numeric Rating Scale[24]	0 - 10	2	
Dyspnea			
Numeric Rating Scale[25]	0 - 10	0.5 - 2	
Edmonton Symptom Assessment Scale (ESAS)[14]	0 - 10	1	
University of California, San Diego Shortness of Breath Questionnaire[26, 27]	0 - 120	5 - 6	
		5	
Fatigue			
Patient-Reported Outcomes Measurement Information System PROMIS SF 8a[28]	8 - 40	2.5 - 4.5 (17 item short form) 3.0 - 5 (7 item short form)	
Edmonton Symptom Assessment Scale (ESAS)[13]	0 - 10	1.8 (deterioration)	
		1	
Caregiver Burden, Impact or Strain			
Zarit Burden Interview (ZBI – 12)[29]	0 - 48	None identified	
Montgomery Borgatta Caregiving Burden Scale – Objective Burden Subscale[30]	6 - 30	None identified	>23 (high score)
Montgomery Borgatta Caregiving Burden – Demand Burden Subscale[30]	4 - 20	None identified	>15 (high score)
Montgomery Borgatta Caregiving Burden – Stress Burden subscale[30]	4 - 20	None identified	>13.5 (high score)

Data Extraction

We created and pilot tested standardized forms for data extraction. Each Web resource or article underwent double review by the study investigators for data abstraction. The second reviewer confirmed the first reviewer's abstracted data for completeness and accuracy. A third reviewer audited a sample of articles by the first two reviewers to ensure consistency in the data abstraction of the articles.

For all articles, reviewers extracted information on general study characteristics (e.g., study design, study period, and follow-up), study participant characteristics, eligibility criteria, interventions, outcome measures and the method of ascertainment, and the results of each outcome, including measures of variability. We completed the data abstraction process using forms created in Excel (Microsoft, Redmond, WA). We used the Excel files to maintain the data and to create detailed evidence tables and summary tables.

Risk of Bias Assessment of Individual Quantitative Studies

Two reviewers independently assessed risk of bias for each quantitative study. For RCTs, we used the Cochrane Risk of Bias Tool, Version 2.[31] For non-randomized studies, we used the Cochrane Risk of Bias Assessment Tool for Non-Randomized Studies of Interventions (ROBINS-I tool).[32] Differences between reviewers were resolved through consensus.

We assessed the individual risk of bias for RCTs using five items:
Risk of bias arising from the randomization process;
Risk of bias due to deviations from the intended interventions: effect of assignment to intervention, and effect of adhering to intervention;
Risk of bias due to missing outcome data;
Risk of bias in measurement of the outcome;
Risk of bias in selection of the reported result.

Following the ROB2 guidance, concerns were expressed only about issues that are likely to affect the ability to draw reliable conclusions from the study. In reaching final judgements, the following considerations applied: judgement of 'High' risk of bias for any individual domain will lead to the result being at 'High' risk of bias overall, and a judgement of 'Some concerns' for any individual domain will lead to the result being at 'Some concerns', etc.

We assessed the individual risk of bias for non-randomized and cohort studies using 7 items:
Bias due to confounding;
Bias in selection of participants into the study;
Bias in classification of interventions;
Bias owing to deviations from intended interventions;
Bias owing to missing data;
Bias in measurement of outcomes;
Bias in selection of the reported results.

Following the ROBINS guidance, judgements were made using the following algorithm:[32]
low risk of bias: the study is judged to be at low risk of bias for all domains,
moderate risk of bias: the study is judged to be at low or moderate risk of bias for all domains,
serious risk of bias: the study is judged to be at serious risk of bias in at least one domain, but not at critical risk of bias in any domain,
critical risk of bias: the study is judged to be at critical risk of bias in at least one domain,
no information: there is no clear indication that the study is at serious or critical risk of bias and there is a lack of information in one or more key domains of bias (a judgement is required for this).

Assessment of Quality of Qualitative Studies

For qualitative studies, we conducted quality assessment, as risk of bias is not relevant. We used the Joanna Briggs Institute Quality Appraisal Checklist[33, 34] to address elements specific to our key questions. Two reviewers independently assessed the methodological quality and resolved differences through consensus.

Data Synthesis and Analysis

For part (b) of each Key Question, we created a set of detailed evidence tables containing all information extracted from eligible studies (see Appendix D). These tables include details of what is included in the interventions; for example, for models of care, details extracted include what disciplines are involved, mode of contact, and content of the intervention. Tables also include details of implementation of the interventions as described in these studies, such as clinician training provided. We synthesized all studies qualitatively. We conducted meta-analyses for outcomes with at least three studies and the studies were sufficiently homogeneous with respect to key variables (population characteristics, study duration, and intervention). Randomized controlled trials and nonrandomized studies were analyzed separately. Statistical significance was set at a two-sided alpha of 0.05. Statistical heterogeneity among studies was evaluated using an I^2 statistic and anticipated statistical heterogeneity. For continuous outcomes, a standardized mean difference was calculated using a random-effects model with DerSimonian and Laird formula. All meta-analyses was conducted using STATA version 14 (College Station, TX).

For part (c) of each key question, we summarized the results of the qualitative studies into categories for each KQ, informed by discussions with our Key Informants. We conducted a review of the qualitative studies to address mechanisms and context for part (c) of each KQ where studies were identified. We based our methods on the 2017 Cochrane guidance, *Qualitative and Implementation Methods Group Guidance Paper 5: Methods for integrating*

qualitative and implementation evidence within intervention effectiveness reviews[35] and Joanna Briggs Institute methods for mixed methods systematic reviews.[36]

For parts (b) and (c) of each key question, model definitions were derived from previous work and revised based on consensus.[37] Once established, two researchers independently reviewed each citation to determine model type.

Finally, we completed an integrative review. The Cochrane guidance defines the integrative review as "combining the findings from different types of studies to produce a more comprehensive synthesis of the evidence on 'what works'", recognizing that a variety of contextual factors, such as characteristics of the local population or setting, are key to intervention implementation and effectiveness (under "real world" conditions). Through the incorporation of qualitative and mixed methods research, the integrative review process can incorporate the patient and caregiver perspective, which is critical for palliative care, and the practicing clinician and health system perspective, which is critical for the integration of palliative care in the ambulatory setting. We completed integration by juxtaposing the findings from the grey literature (part (a) in each question) with the systematic review (part (b) in each question) with the identified categories from the review of qualitative studies (part (c) of each question). We focused particularly on KQ3 and KQ5 where studies were identified across all parts. We integrated categories of what is available (e.g., components of what is included in integrated palliative care interventions) from qualitative studies with evidence from effectiveness studies. We used categories informed by models of what is included in integrated ambulatory palliative care[38], the Consolidated Framework for Implementation Research (CFIR) adapted for complex interventions[38], a prior AHRQ project on key implementation factors for quality and safety studies[39], and refined through Key Informant input. This process helped address, in particular, the elements of the part (c) questions on why and how some types of interventions may be effective and others are not, when and which patients may benefit from these interventions, and how palliative care approaches can best be integrated into ambulatory care.

Grading the Strength of the Body of Evidence

At the completion of our systematic review, we graded the strength of evidence on critical outcomes for quantitative studies by using the grading scheme recommended by the Methods Guide for Conducting Comparative Effectiveness Reviews. We defined the critical outcomes as those most important for making decisions; we identified these a priori with input from the Technical Expert Panel.

The critical outcomes include:
Patient health-related quality of life
Patient symptom burden
Patient symptoms of depression
Patient satisfaction
Caregiver satisfaction
Advance directive documentation

Following this standard EPC approach, for each critical outcome, we assessed the number of studies, their study designs, the study limitations (i.e., risk of bias and overall methodological quality), the directness of the evidence to the Key Questions, the consistency of study results, the precision of any estimates of effect, the likelihood of reporting bias, and the overall findings across studies. Based on these assessments, we assigned a strength of evidence rating as being either high, moderate, or low, or insufficient evidence to estimate an effect or draw a conclusion (Table 5). Investigators writing each section completed the strength of evidence grading. The team members reviewed the assigned grade and conflicts were resolved through consensus. We used the grading scheme recommended in the AHRQ Methods Guide for Effectiveness and Comparative Effectiveness Reviews (Methods Guide). We considered the following domains: study limitations, directness, consistency, and precision.[40]

We classified the strength of evidence pertaining to the KQs into four categories:

High (high confidence that the evidence reflects the true effect and further research is very unlikely to change our confidence in the estimate of effect)
One or more RCTs
Low study limitations
Direct, consistent, and precise
Moderate (moderate confidence that the evidence reflects the true effect, and further research may change our confidence in the estimate of effect)
One or more RCTs
Low study limitations, and some concerns
Direct, consistent, and precise
Low (low confidence that the evidence reflects the true effect and further research is likely to change our confidence in the estimate of the effect and is likely to change the effect estimate)
One or no RCT
High study limitations or some concerns
At least two of the following: indirect, inconsistent, or imprecise
Insufficient (evidence is unavailable or insufficient to assess with any confidence).
One or no RCT
High study limitations for RCTs or serious or critical study limitations for a cohort study
At least two of the following: indirect, inconsistent, or imprecise

Table A-12. Definitions of the grades of overall strength of evidence

Grade	Definition
High	We are very confident that the estimate of effect lies close to the true effect for this outcome. The body of evidence has few or no deficiencies. We believe that the findings are stable (i.e., another study would not change the conclusions).
Moderate	We are moderately confident that the estimate of effect lies close to the true effect for this outcome. The body of evidence has some deficiencies. We believe that the findings are likely to be stable, but some doubt remains.
Low	We have limited confidence that the estimate of effect lies close to the true effect for this outcome. The body of evidence has major or numerous deficiencies (or both). We believe that additional evidence is needed before concluding either that the findings are stable or that the estimate of effect is close to the true effect.
Insufficient	We have no evidence, we are unable to estimate an effect, or we have no confidence in the estimate of effect for this outcome. No evidence is available, or the body of evidence has unacceptable deficiencies, precluding reaching a conclusion.

Peer Review and Public Commentary

We invited experts in palliative care and individuals representing stakeholder and user communities to provide external peer review of this review; AHRQ and an associate editor also provided comments. We posed the revised draft report on the AHRQ website for four weeks to elicit public comment (posted 5 August 2020). Reviewer comments were addressed, revising the report as appropriate. A disposition of comments table of peer and public comments was posted on the EHC website three months after the Agency posted the final review.

Definition of Terms

The following definitions are used in this report.

Ambulatory settings: Includes settings such as hospital outpatient departments and clinicians' offices, particularly primary care, but also including geriatrics, nephrology, pulmonology, cardiology and neurology
Chronic illness: An illness that lasts one year or more and requires ongoing medical attention and/or limits activities of daily living.

Clinician: A healthcare professional qualified in the clinical practice of medicine, such as physicians, nurses, pharmacists, social workers, or other allied health professionals.[41]
Consultative care model: An approach to care delivery where a clinician serves in a consultant role with provision of palliative advice and does not necessarily assume primary responsibility of care.[42]
Educational materials and resources: Include pamphlets, curricula, Web sources, and videos designed to provide information about integrating palliative care and palliative care options in ambulatory care.
Guidelines and position statements: Clinical practice guidelines and position statements from key U.S. health care professional and other organizations specifically relevant to integrating palliative care into serious illness chronic care.
Integrative review: This method allows for the combination of diverse methodologies.[43] We use this approach to examine qualitative and process evaluation literature (such as interviews with patients and families and implementation studies) to address how interventions work and evidence for how they should best be included in care, and to integrate this with the effectiveness literature. Combining the findings from different types of studies to produce a more comprehensive synthesis of the evidence on 'what works' and how.[35]
Multimodal interventions: For the purposes of this review, combinations of the different types of included specific interventions: identification of patients, education for patients and caregivers, shared decision-making tools, and/or clinician education.
Models: Care delivery structures.
Palliative care: Care, services, or programs for patients with serious life-threatening illness and conditions and their caregivers, with the primary intent of relieving suffering and improving health-related quality of life, including dimensions of physical, psychological/emotional, social, and spiritual well-being.[36] Note that other terms, such as supportive care, may be similarly used. Hospice care is a type of palliative care but is not included in this review as it is not delivered in ambulatory care.
Patient education: This can be conducted either individually or as part of a group or community, including through methods such as in-person, telephone, online or other electronic, print or audio-visual educational materials.[37]
Prediction models: Modeling of patient and illness factors to predict the likelihood of patient outcomes, such as hospitalizations.
Primary palliative care: Care in palliative care domains for relevant populations provided by non-palliative care specialists, such as by primary care clinicians.[44]
Process evaluation (also a type of implementation study): Research focusing on mechanisms (how and why something can be successfully implemented) and contextual issues (population, setting, barriers and facilitators).[35] Process evaluation studies include process studies that report on why and how interventions work with similar interventions, health conditions and contexts.[45] They may be:
conducted alongside effectiveness studies
conducted after the effectiveness study on the same groups
unrelated to effectiveness studies
Provider education: Used to describe a variety of interventions including educational workshops, meetings (e.g., traditional Continuing Medical Education [CME]), lectures (in-person or computer-based), educational outreach visits (by a trained representative who meets with providers in their practice settings to disseminate information with the intent of changing the providers' practice). The same term also is used to describe the distribution of educational materials (electronically published or printed clinical practice guidelines and audio-visual materials).[46] This review focuses on materials that include education about integrating palliative care into ambulatory care.
Shared care model: An approach to care delivery where there is joint participation of non-palliative clinicians and palliative care clinicians working together in relation to an individual's care. Shared care models may also include systematic cooperation where different systems work together with various levels and disciplines of clinicians.[47]
Shared decision-making tools: These are patient-facing and/or clinician-facing tools to help make decisions that reflect medical evidence and patient goals for care relevant to palliative care, such as advance care planning tools to aid with decisions about treatment options and preferences for future care.[48] For the purposes of this review, we focused on tools for serious illnesses and conditions in ambulatory care.
Triggers: Also known as screening criteria; indicators that someone may benefit from palliative care services. These may include patient or disease characteristics, palliative care needs, functional status decline or persistent or worsening symptoms, or high health care needs.
Website: A collection of Web pages which are grouped together and connected.
Webpage: Document which can be displayed in a Web browser.
Web resource: Specific resource listed on a Web page.

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42. Luckett T, Phillips J, Agar M, et al. Elements of effective palliative care models: a rapid review. BMC Health Services Research. 2014;14(1):136-. doi: 10.1186/1472-6963-14-136. PMID: 103815400. Language: English. Entry Date: 20150123. Revision Date: 20190110. Publication Type: journal article.

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44. Quill TE, Abernethy AP. Generalist plus specialist palliative care--creating a more sustainable model. N Engl J Med. 2013 Mar 28;368(13):1173-5. doi: 10.1056/NEJMp1215620. PMID: 23465068.

45. Cargo M, Harris J, Pantoja T, et al. Cochrane Qualitative and Implementation Methods Group guidance series-paper 4: methods for assessing evidence on intervention implementation. J Clin Epidemiol. 2018 May;97:59-69. doi: 10.1016/j.jclinepi.2017.11.028. PMID: 29223325.

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47. Paquette-Warren J, Vingilis E, Greenslade J, et al. What do practitioners think? A qualitative study of a shared care mental health and nutrition primary care program. Int J Integr Care. 2006 Oct 9;6:e18. doi: 10.5334/ijic.164. PMID: 17041680.

48. Legare F, Ratte S, Gravel K, et al. Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. Patient Educ Couns. 2008 Dec;73(3):526-35. doi: 10.1016/j.pec.2008.07.018. PMID: 18752915.

Appendix B. List of Excluded Studies

Excluded Websites

Table B-1. Excluded Web pages

Organization	Website URL	Website Resource URL	Exclusion Criteria
AARP: American Association of Retired Persons	https://www.aarp.org/	https://www.aarp.org/caregiving/answers/info-2017/what-is-palliative-care.html	No eligible resources found
AARP: American Association of Retired Persons	https://www.aarp.org/	https://search.aarp.org/gss/everywhere?q=palliative%20care&firstResult=11	No eligible resources found
Alzheimer's Association	https://www.alz.org/	https://www.alz.org/professionals/health-systems-clinicians/care-planning	No eligible resources found
Alzheimer's Association	https://www.alz.org/	https://www.alz.org/help-support/caregiving	No eligible resources found
Alzheimer's Association	https://www.alz.org/	https://www.alz.org/professionals/health-systems-clinicians/for-patients-caregivers/downloadable-resources	No eligible resources found
American Academy of Family Physicians	https://www.aafp.org/home.html	https://www.aafp.org/cme/browse/topic.tag-illness.html	No eligible resources found
American Academy of Family Physicians	https://www.aafp.org/home.html	https://www.aafp.org/cme/cme-topic/all/hospice-and-palliative-care.html	No eligible resources found
American Academy of Hospice and Palliative Medicine	http://aahpm.org/	http://aahpm.org/education/meetings	No eligible resources found
American Academy of Hospice and Palliative Medicine	http://aahpm.org/	http://aahpm.org/education/self-study	No eligible resources found
American Academy of Hospice and Palliative Medicine	http://aahpm.org/	http://aahpm.org/self-study/primer	No eligible resources found
American Academy of Hospice and Palliative Medicine	http://aahpm.org/	http://aahpm.org/career/overview	No eligible resources found
American College of Cardiology	https://www.acc.org	https://www.acc.org/guidelines/guidelines-search#sort=relevancy&f:TopicSearchFacet=[Heart%20Failure%20and%20Cardiomyopathies]	No eligible resources found
American College of Cardiology	https://www.acc.org	https://www.acc.org/tools-and-practice-support/clinical-toolkits/heart-failure-practice-solutions	No eligible resources found
American College of Physicians	https://www.acponline.org/	https://www.acponline.org/cme-moc/online-learning-center/palliative-care-0	No eligible resources found
American College of Physicians	https://www.acponline.org/	https://www.acponline.org/system/files/documents/about_acp/chapters/co/17mtg/robinson.pdf	No eligible resources found
American College of Physicians	https://www.acponline.org/	https://www.acponline.org/sites/default/files/images/about_acp/chapters/sc/17mtg/overstreet_primary_palliative_care.pdf	No eligible resources found
American College of Physicians	https://www.acponline.org/	https://www.acponline.org/system/files/documents/clinical_information/resources/end_of_life_care/serious_ill.pdf	No eligible resources found
American College of Physicians	https://www.acponline.org/	https://www.acponline.org/clinical-information/clinical-resources-products/end-of-life-care	No eligible resources found

Organization	Website URL	Website Resource URL	Exclusion Criteria
American Geriatrics Society	https://www.americangeriatrics.org/	https://geriatricscareonline.org/ProductAbstract/reference-guide-to-ethics-domains-relevant-to-palliative-care/CL021	No eligible resources found
American Geriatrics Society	https://www.americangeriatrics.org/	https://geriatricscareonline.org/toc/Framework-for-Decision-making-for-Older-Adults/CL026	No eligible resources found
American Geriatrics Society	https://www.americangeriatrics.org/	https://geriatricscareonline.org/ProductTypeStore/webinars/17/	No eligible resources found
American Geriatrics Society	https://www.americangeriatrics.org/	https://geriatricscareonline.org/ProductAbstract/multimorbidity-toolkit/TK011	No eligible resources found
American Geriatrics Society	https://www.americangeriatrics.org/	https://geriatricscareonline.org/ProductTypeStore/mobile-apps/13/	No eligible resources found
American Heart Assocation	www.heart.org	https://www.heart.org/en/health-topics/heart-failure/living-with-heart-failure-and-managing-advanced-hf/communicating-with-your-advanced-heart-failure-healthcare-team	No eligible resources found
American Heart Assocation	www.heart.org	https://www.heart.org/en/health-topics/heart-failure/living-with-heart-failure-and-managing-advanced-hf/overcoming-barriers-to-shared-decision-making	No eligible resources found
American Heart Assocation	www.heart.org	https://www.heart.org/en/health-topics/heart-failure/heart-failure-tools-resources	No eligible resources found
American Heart Assocation	www.heart.org	https://professional.heart.org/professional/GuidelinesStatements/UCM_492626_Guidelines-Statements-Search-Page.jsp	No eligible resources found
American Lung Association	www.lung.org	https://www.lung.org/lung-health-and-diseases/lung-disease-lookup/lung-cancer/navigator/diagnosedpathway/diagnosed-palliative.html	No eligible resources found
American Nurses Association	www.nursingworld.org	www.nursingworld.org/~497158/globalassets/practiceandpolicy/health-policy/palliativecareprofessionalissuespanelcallforaction.pdf	No eligible resources found
American Society of Nephrology	www.asn-online.org	https://www.asn-online.org/education/cme/	No eligible resources found
American Thoracic Society	www.thoracic.org	https://www.thoracic.org/professionals/clinical-resources/	No eligible resources found
American Thoracic Society	www.thoracic.org	https://www.thoracic.org/professionals/education/	No eligible resources found
American Thoracic Society	www.thoracic.org	https://www.thoracic.org/statements/health-care.php	No eligible resources found
American Thoracic Society	www.thoracic.org	https://www.capc.org/	No eligible resources found
Cambia Health Foundation	https://www.cambiahealthfoundation.org/	https://www.cambiahealthfoundation.org/resources/palliative-care-resources.html	No eligible resources found
Center for Medicare and Medicaid Services	https://www.cms.gov/	https://innovation.cms.gov/initiatives/comprehensive-ESRD-care/	No eligible resources found
Center for Medicare and Medicaid Services	https://www.cms.gov/	https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-MedicaidCoordination	No eligible resources found
Center to Advance Palliative Care	www.capc.org	https://www.capc.org/training/	No eligible resources found
Center to Advance Palliative Care	www.capc.org	https://www.capc.org/training/an-in-depth-look-at-palliative-care-and-its-services/	No eligible resources found
Center to Advance Palliative Care	www.capc.org	https://www.capc.org/training/continuing-education-courses-by-specialty-or-discipline/	No eligible resources found

Organization	Website URL	Website Resource URL	Exclusion Criteria
Center to Advance Palliative Care	www.capc.org	https://www.capc.org/training/preventing-crises-through-whole-patient-care/care-coordination/	No eligible resources found
Center to Advance Palliative Care	www.capc.org	https://www.capc.org/about/palliative-care/	No eligible resources found
Center to Advance Palliative Care	www.capc.org	https://www.capc.org/toolkits/starting-the-program/designing-an-office-or-clinic-palliative-care-program/	No eligible resources found
Coalition for Supportive Care of Kidney Patients	https://www.kidneysupportivecare.org/	https://www.kidneysupportivecare.org/for-patients-families/dialysis/	No eligible resources found
Coalition for Supportive Care of Kidney Patients	https://www.kidneysupportivecare.org/	https://www.kidneysupportivecare.org/for-patients-families/additional-resources/	No eligible resources found
Coalition for Supportive Care of Kidney Patients	https://www.kidneysupportivecare.org/	https://www.kidneysupportivecare.org/palliative-care/	No eligible resources found
Council on Social Work Education	https://www.cswe.org/Home.aspx	https://www.cswe.org/Home.aspxN/A – not relevant to Key Questions	No eligible resources found
End-of-Life Nursing Education Consortium	https://www.aacnnursing.org/ELNEC	https://www.aacnnursing.org/ELNEC/Courses	No eligible resources found
EPEC: Education in Palliative and End of Life Care	https://www.bioethics.northwestern.edu/programs/epec/about/index.html	https://www.bioethics.northwestern.edu/programs/epec/curricula/index.html	No eligible resources found
EPEC: Education in Palliative and End of Life Care	https://www.bioethics.northwestern.edu/programs/epec/curricula/caregivers.html	https://www.bioethics.northwestern.edu/programs/epec/curricula/caregivers.html	No eligible resources found
Gerontological Advanced Practice Nurses Association	https://www.gapna.org/	https://www.gapna.org/resources/crc/deborah-dunn-and-michelle-moccia-discuss-ethics-end-life-care	No eligible resources found
Gerontological Advanced Practice Nurses Association	https://www.gapna.org/	https://library.gapna.org/gapna/sessions/1272/view	No eligible resources found
Gerontological Advanced Practice Nurses Association	https://www.gapna.org/	https://library.gapna.org/gapna/specialties/9/view/0	No eligible resources found
Gordon and Betty Moore Foundation	https://www.moore.org/	https://www.moore.org/search-results?indexCatalogue=default&searchQuery=palliative&wordsMode=0	No eligible resources found
Health Resources and Services Administration	https://www.hrsa.gov/	https://www.hrsa.gov/library/health-center-resource-clearinghouse	No eligible resources found
Hospice and Palliative Nurses Association	https://advancingexpertcare.org/	https://advancingexpertcare.org/elearning	No eligible resources found
Hospice and Palliative Nurses Association	https://advancingexpertcare.org/	https://advancingexpertcare.org/HPNAweb/Education/Polaris_Modules.aspx	No eligible resources found
Hospice and Palliative Nurses Association	https://advancingexpertcare.org/	https://advancingexpertcare.org/certification-review-courses	No eligible resources found
Hospice and Palliative Nurses Association	https://advancingexpertcare.org/	https://advancingexpertcare.org/aprn-externship	No eligible resources found
Hospice and Palliative Nurses Association	https://advancingexpertcare.org/	https://advancingexpertcare.org/HPNA/Education/HPNA_Store/iCore/Store/StoreLayouts/Store_Home.aspx?hkey=dfd17aa6-a95c-4652-9f27-245400487f65	No eligible resources found

Organization	Website URL	Website Resource URL	Exclusion Criteria
John A. Hartford Foundation	https://www.johnahartford.org/	https://www.johnahartford.org/search/results?keywords=palliative+care	No eligible resources found
National Alliance for Caregiving	https://www.caregiving.org/	https://www.caregiving.org/guidebooks/	No eligible resources found
National Alliance for Caregiving	https://www.caregiving.org/	https://www.caregiving.org/resources/	No eligible resources found
National Alliance for Caregiving	https://www.caregiving.org/	https://www.caregiving.org/?s=palliative	No eligible resources found
National Association of Social Workers	https://www.socialworkers.org/	https://www.socialworkers.org/Practice/Aging/Aging-Tools?udt_18083_param_page=3	No eligible resources found
National Association of Social Workers	https://www.socialworkers.org/	https://www.socialworkers.org/Practice/Aging/Aging-Professional-Development/ESPEC	No eligible resources found
National Hospice and Palliative Care Organization	https://www.nhpco.org/	https://www.nhpco.org/online-course/community-based-palliative-care	No eligible resources found
National Hospice and Palliative Care Organization	https://www.nhpco.org/	https://www.nhpco.org/patients-and-caregivers/about-palliative-care/palliative-care-faqs/	No eligible resources found
National Hospice and Palliative Care Organization	https://www.nhpco.org/	https://www.nhpco.org/patients-and-caregivers/advance-care-planning/	No eligible resources found
National Hospice and Palliative Care Organization	https://www.nhpco.org/	https://www.nhpco.org/wp-content/uploads/2019/04/cc_now_what-1.pdf	No eligible resources found
National Hospice and Palliative Care Organization	https://www.nhpco.org/	https://www.nhpco.org/wp-content/uploads/2019/04/How_Can_Palliative_Care_Help_Me.pdf	No eligible resources found
National Hospice and Palliative Care Organization	https://www.nhpco.org/	https://www.nhpco.org/wp-content/uploads/2019/04/A_Guide_for_Clinicians.pdf	No eligible resources found
National Hospice and Palliative Care Organization	https://www.nhpco.org/	https://www.nhpco.org/wp-content/uploads/2019/04/NHPCO_Professional_flier.pdf	No eligible resources found
National Institute of Nursing Research	www.ninr.nih.gov	https://www.ninr.nih.gov/newsandinformation/conversationsmatter/conversationsmatter-patients	No eligible resources found
National Institute on Aging	https://www.nia.nih.gov/	https://www.nia.nih.gov/health/supporting-older-patients-chronic-conditions	No eligible resources found
National Kidney Foundation	www.kidney.org	https://www.kidney.org/atoz/content/newly-diagnosed-heres-what-you-need-know	No eligible resources found
National Kidney Foundation	www.kidney.org	https://www.kidney.org/professionals	No eligible resources found
National Kidney Foundation	www.kidney.org	https://www.kidney.org/professionals/tools	No eligible resources found
National Kidney Foundation	www.kidney.org	https://www.kidney.org/CKDintercept	No eligible resources found
National Kidney Foundation	www.kidney.org	https://education.kidney.org/ckdinformspring	No eligible resources found
National Kidney Foundation	www.kidney.org	https://www.kidney.org/content/applying-palliative-care-skillst-nephrology-care	No eligible resources found
National Kidney Foundation	www.kidney.org	https://www.kidney.org/atoz/content/how-does-palliative-care-improve-quality-life-kidney-patients	No eligible resources found
Pew Charitable Trusts	https://www.pewtrusts.org/en	https://www.pewtrusts.org/en/topics/health-care	No eligible resources found
Physician Assistants in Hospice and Palliative Medicine	https://pahpm.org/	https://pahpm4.wildapricot.org/Continuing-Education	No eligible resources found

Organization	Website URL	Website Resource URL	Exclusion Criteria
Physician Assistants in Hospice and Palliative Medicine	https://pahpm.org/	https://fourseasonsconsulting.teleioscn.org/education/palliative-care-immersion-course	No eligible resources found
Physician Assistants in Hospice and Palliative Medicine	https://pahpm.org/	https://www.bioethics.northwestern.edu/programs/epec/	Linked to EPEC
Physician Assistants in Hospice and Palliative Medicine	https://pahpm.org//	https://pallcare.hms.harvard.edu/	No eligible resources found
Physician Assistants in Hospice and Palliative medicine	https://pahpm.org//	https://pallcare.hms.harvard.edu/courses	No eligible resources found
Physician Assistants in Hospice and Palliative Medicine	https://pahpm.org//	https://pallcare.hms.harvard.edu/training	No eligible resources found
Physician Assistants in Hospice and Palliative Medicine	https://pahpm.org//	https://pallcare.hms.harvard.edu/seminars	No eligible resources found
Social Works Hospice and Palliative Care Network	https://www.swhpn.org/	https://swhpn.mclms.net/en/package/282/course/326/view	No eligible resources found
Society of General Internal Medicine	https://www.sgim.org/#	N/A – not relevant to Key Questions	No eligible resources found
Society of Pain and Palliative Care Pharmacists	https://www.palliativepharmacist.org/site_home.cfm	https://www.palliativepharmacist.org/site_page.cfm?pk_association_webpage_menu=3619&pk_association_webpage=8210	No eligible resources found
Society of Pain and Palliative Care Pharmacists	https://www.palliativepharmacist.org/site_home.cfm	https://s3.amazonaws.com/amo_hub_content/Association677/files/P%26HC%20Guidline%20Doc%20-%20Published.pdf	No eligible resources found

URL= Universal Resource Locator

Excluded Articles

Baylor Health System Supportive and Palliative Care Services. H&HN: Hospitals & Health Networks. 2014;88(8):41-2. PMID: 107874000. Language: English. Entry Date: 20140821. Revision Date: 20150712. Publication Type: Journal Article. **-No original data**

Integrating CAM research and practice: a focus on outcome measures -- abstracts from the 3rd annual IN-CAM Symposium November 4th & 5th, 2006, Calgary, Canada. Journal of Complementary & Integrative Medicine. 2006;3(1):1-46. PMID: 106245519. Language: English. Entry Date: 20070302. Revision Date: 20150711. Publication Type: Journal Article. **-Not relevant to key questions**

Relias Media. Integrating palliative care in case management can work. Case Management Advisor. 2016;27(4):3-5. PMID: 114159764. Language: English. Entry Date: 20170518. Revision Date: 20170518. Publication Type: Article. Journal Subset: Nursing. **-No original data**

SUPPORTIVE AND PALLIATIVE CARE IN PRIMARY CARE. GM: Midlife & Beyond. 2015;45(7):37-. PMID: 109619371. Language: English. Entry Date: 20150923. Revision Date: 20150923. Publication Type: Journal Article. Journal Subset: Biomedical. **-No original data**

The SUMMIT ambulatory-ICU primary care model for medically and socially complex patients in an urban federally qualified health center: study design and rationale. Addiction science & clinical practice. 2018;13(1):27-. doi: 10.1186/s13722-018-0128-y. PMID: CN-01925167. **-Not relevant to key questions**

Abernethy AP, McDonald CF, Frith PA, et al. Effect of palliative oxygen versus room air in relief of breathlessness in patients with refractory dyspnoea: a double-blind, randomised controlled trial. Lancet. 2010;376 North American Edition(9743):784-93. doi: 10.1016/S0140-6736(10)61115-4. PMID: 105091250. Language: English. Entry Date: 20101008. Revision Date: 20161125. Publication Type: journal article. **-Not relevant to key questions**

Abu Al Hamayel N, Isenberg SR, Hannum SM, et al. Older Patients' Perspectives on Quality of Serious Illness Care in Primary Care. Am J Hosp Palliat Care. 2018 Oct;35(10):1330-6. doi: 10.1177/1049909118771675. PMID: 29682975. **-Patients do not have serious life-threatening chronic illness or conditions**

Scuffham PA, Mihala G, Ward L, McMurray A, Connor M. Evaluation of the Gold Coast Integrated Care for patients with chronic disease or high risk of hospitalisation through a non-randomised controlled clinical trial: a pilot study protocol. *BMJ Open*. 2017;7(6):e016776. Published 2017 Jul 2. doi:10.1136/bmjopen-2017-016776 . **-No original data**

Kavarthapol Jayaraman, Vinothkumar. Outcomes of stage 4 & 5 chronic kidney disease patients attending 2 different models of outpatient care. http://www.who.int/trialsearch/Trial2.aspx?TrialID=ACTRN12611001117909. 2011 PMID: CN-01846776. **-Not relevant to key questions**

Agarwal R, Shuk E, Romano D, et al. A mixed methods analysis of patients' advance care planning values in outpatient oncology: Person-Centered Oncologic Care and Choices (P-COCC). Support Care Cancer. 2020 Mar;28(3):1109-19. doi: 10.1007/s00520-019-04910-1. PMID: 31197540. **-Not relevant to key questions**

Aggarwal SK, Ghosh A, Cheng MJ, et al. Initiating pain and palliative care outpatient services for the suburban underserved in Montgomery County, Maryland: Lessons learned at the NIH Clinical Center and MobileMed. Palliative & Supportive Care. 2016;14(4):381-6. doi: 10.1017/S1478951515001030.

PMID: 116921770. Language: English. Entry Date: 20170113. Revision Date: 20170316. Publication Type: journal article. Journal Subset: Biomedical. **-Fewer than 10 participants**

Ahluwalia SC, Bekelman DB, Huynh AK, et al. Barriers and Strategies to an Iterative Model of Advance Care Planning Communication. American Journal of Hospice & Palliative Medicine. 2015;32(8):817-23. doi: 10.1177/1049909114541513. PMID: 110716484. Language: English. Entry Date: 20160123. Revision Date: 20170203. Publication Type: Article. **-No full report (e.g. conference or meeting abstract)**

Ahluwalia SC, Chen C, Raaen L, et al. A Systematic Review in Support of the National Consensus Project Clinical Practice Guidelines for Quality Palliative Care, Fourth Edition. J Pain Symptom Manage. 2018 Dec;56(6):831-70. doi: 10.1016/j.jpainsymman.2018.09.008. PMID: 30391049. **-No original data**

Ahluwalia SC, Fried TR. Physician factors associated with outpatient palliative care referral. Palliat Med. 2009 Oct;23(7):608-15. doi: 10.1177/0269216309106315. PMID: 19460830. **-Not relevant to key questions**

Ahluwalia SC, Levin JR, Lorenz KA, et al. Missed opportunities for advance care planning communication during outpatient clinic visits. J Gen Intern Med. 2012 Apr;27(4):445-51. doi: 10.1007/s11606-011-1917-0. PMID: 22038469. **-Not relevant to key questions**

Ahluwalia SC, Levin JR, Lorenz KA, et al. 'There's no cure for this condition': How physicians discuss advance care planning in heart failure. Patient Education & Counseling. 2013;91(2):200-5. doi: 10.1016/j.pec.2012.12.016. PMID: 104070357. Language: English. Entry Date: 20140627. Revision Date: 20150710. Publication Type: Journal Article. **-Patients not being seen in ambulatory settings**

Ahmed N, Hughes P, Winslow M, et al. A randomised controlled trial of an holistic needs assessment questionnaire in a supportive and palliative care service using the sheffield profile for assessment and referral for care (SPARC): a mixed methods study. Palliative medicine. 2014;28(6):567-. doi: 10.1177/0269216314532748. PMID: CN-01010267. **-Not a U.S. population**

Ahmed N, Hughes P, Winslow M, et al. Feasibility study of the sheffield profile for assessment and referral for care (SPARC): a holistic needs questionnaire. Palliative medicine. 2012;26(4):542-. doi: 10.1177/0269216312446391. PMID: CN-01006857. **-Not a U.S. population**

Ahmed NN, Farnie M, Dyer CB. The effect of geriatric and palliative medicine education on the knowledge and attitudes of internal medicine residents. J Am Geriatr Soc. 2011 Jan;59(1):143-7. doi: 10.1111/j.1532-5415.2010.03235.x. PMID: 21226684. **-Other: Trainee education**

Ahmed NN, Farnie M, Dyer CB. The effect of geriatric and palliative medicine education on the knowledge and attitudes of internal medicine residents. Journal of the American Geriatrics Society. 2011;59(1):143-7. doi: 10.1111/j.1532-5415.2010.03235.x. PMID: 104989650. **-Other: Trainee education**

Alderman JS, Nair B, Fox MD. Residency training in advance care planning: can it be done in the outpatient clinic? Am J Hosp Palliat Care. 2008 Jun-Jul;25(3):190-4. doi: 10.1177/1049909108315301. PMID: 18573995. **-Other: Trainee education**

Alexander Cole C, Wilson E, Nguyen PL, et al. Scaling Implementation of the Serious Illness Care Program Through Coaching. J Pain Symptom Manage. 2020 Mar 20doi: 10.1016/j.jpainsymman.2020.03.008. PMID: 32201309. **-Other: No control group**

Allen SL, Davis KS, Rousseau PC, et al. Advanced Care Directives: Overcoming the Obstacles. J Grad Med Educ. 2015 Mar;7(1):91-4. doi: 10.4300/jgme-d-14-00145.1. PMID: 26217430. **-Other: Trainee education**

Andreoni VM, Obrecht JA, Bowden VR. Palliative care resources for the health professional. MCN Am J Matern Child Nurs. 2007 Sep-Oct;32(5):305-10. doi: 10.1097/01.NMC.0000288002.72382.9f. PMID: 17728593. **-No original data**

Arnett K, Sudore RL, Nowels D, et al. Advance Care Planning: Understanding

Clinical Routines and Experiences of Interprofessional Team Members in Diverse Health Care Settings. Am J Hosp Palliat Care. 2017 Dec;34(10):946-53. doi: 10.1177/1049909116666358. PMID: 27599724. **-No full report (e.g. conference or meeting abstract)**

Aslakson RA, Schuster ALR, Lynch TJ, et al. Developing the Storyline for an Advance Care Planning Video for Surgery Patients: Patient-Centered Outcomes Research Engagement from Stakeholder Summit to State Fair. J Palliat Med. 2018 Jan;21(1):89-94. doi: 10.1089/jpm.2017.0106. PMID: 28817359. **-Patients not being seen in ambulatory settings**

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Zimmermann CJ, Jhagroo RA, Wakeen M, et al. Opportunities to Improve Shared Decision Making in Dialysis Decisions for Older Adults with Life-Limiting Kidney Disease: A Pilot Study. Journal of Palliative Medicine. 2020. **-Other: No control group**

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Excluded Reviews

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10.12968/ijpn.2015.21.9.430. PMID: 110128803. Language: English. Entry Date: 20151008. Revision Date: 20151009. Publication Type: Article. **-No original data**
Burridge L, Winch S, Clavarino A. Reluctance to care: a systematic review and development of a conceptual framework. Cancer Nurs. 2007 Mar-Apr;30(2):E9-19. doi: 10.1097/01.NCC.0000265298.17394.e0. PMID: 17413772. **-Patient population is cancer-only**
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Gardiner C, Gott M, Ingleton C. Factors supporting good partnership working between generalist and specialist palliative care services: a systematic review. Br J Gen Pract. 2012 May;62(598):e353-62. doi: 10.3399/bjgp12X641474. PMID: 22546595. **-No original data**
Ghosh A, Dzeng E, Cheng MJ. Interaction of palliative care and primary care. Clinics in Geriatric Medicine. 2015;31(2):207-18. doi: 10.1016/j.cger.2015.01.001. PMID: 109584144. Language: English. Entry Date: 20150923. Revision Date: 20160206. Publication Type: journal article. **-No original data**
Green E, Knight S, Gott M, et al. Patients' and carers' perspectives of palliative care in general practice: A systematic review with narrative synthesis. Palliative Medicine. 2018;32(4):833-50. doi: 10.1177/0269216317748862. PMID: 128758466. Language: English. Entry Date: 20180403. Revision Date: 20180522. Publication Type: Article. **-No original data**
Ivany E, While A. Understanding the palliative care needs of heart failure patients. British Journal of Community Nursing. 2013;18(9):441-5. PMID: 104223894. Language: English. Entry Date: 20130910. Revision Date: 20150820. Publication Type: Journal Article. **-No original data**
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Lakin JR, Block SD, Billings JA, et al. Improving Communication About Serious Illness in Primary Care: A Review. JAMA Intern Med. 2016 Sep 1;176(9):1380-7. doi: 10.1001/jamainternmed.2016.3212. PMID: 27398990. **-No original data**
Lakin JR, Block SD, Billings JA, et al. Improving Communication About Serious Illness in Primary Care: A Review. JAMA Internal Medicine. 2016;176(9):1380-7. doi: 10.1001/jamainternmed.2016.3212. PMID: 118055118. Language: English. Entry Date: 20180626. Revision Date: 20180723. Publication Type: journal article. **-No original data**
McCaffrey N, Bradley S, Ratcliffe J, et al. What Aspects of Quality of Life Are Important From Palliative Care Patients' Perspectives? A Systematic Review of Qualitative Research. J Pain Symptom Manage. 2016 Aug;52(2):318-28.e5. doi:

10.1016/j.jpainsymman.2016.02.012. PMID: 27216362. **- Not a U.S. population**
Meeker MA, McGinley JM, Jezewski MA. Metasynthesis: Dying adults' transition process from cure-focused to comfort-focused care. J Adv Nurs. 2019 Oct;75(10):2059-71. doi: 10.1111/jan.13970. PMID: 30734354. **-No original data**
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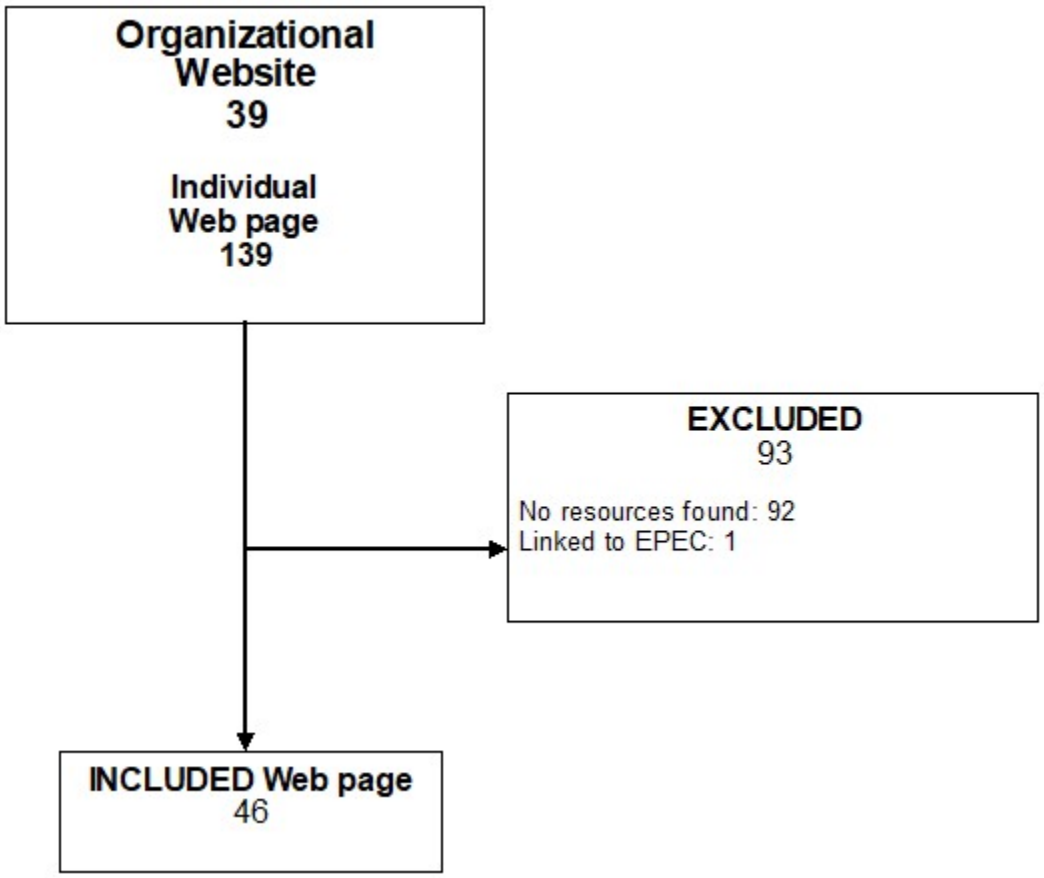
Ostlund U, Brown H, Johnston B. Dignity conserving care at end-of-life: a narrative review. Eur J Oncol Nurs. 2012 Sep;16(4):353-67. doi: 10.1016/j.ejon.2011.07.010. PMID: 21917517. **- Not a U.S. population**
Raymond M, Warner A, Davies N, et al. Palliative and end of life care for people with dementia: lessons for clinical commissioners. Prim Health Care Res Dev. 2014 Oct;15(4):406-17. doi: 10.1017/s146342361300039x. PMID: 24280024. **-No original data**
Robinson L, Iliffe S, Brayne C, et al. Primary care and dementia: 2. Long-term care at home: psychosocial interventions, information provision, carer support and case management. International Journal of Geriatric Psychiatry. 2010;25(7):657-64. doi: 10.1002/gps.2405. PMID: 105038552. Corporate Author: DeNDRoN Primary Care Clinical Studies Group. Language: English. Entry Date: 20100820. Revision Date: 20170928. Publication Type: journal article. **- Not relevant to key questions**
Rocker G, Downar J, Morrison RS. Palliative care for chronic illness: driving change. Cmaj. 2016 Dec 6;188(17-18):E493-e8. doi: 10.1503/cmaj.151454. PMID: 27551031. **-No original data**
Roger KS, Roger KS. A literature review of palliative care, end of life, and dementia. Palliative & Supportive Care. 2006;4(3):295-303. PMID: 106189195. Language: English. Entry Date: 20071109. Revision Date: 20191114. Publication Type: journal article. **-No original data**
Roger KS. A literature review of palliative care, end of life, and dementia. Palliat Support Care. 2006 Sep;4(3):295-303. doi: 10.1017/s1478951506060378. PMID: 17066971. **-No original data**
Simonic A, Furlan M, Ravnjak T, et al. Caring for caregivers: a right way to do it? Curr Opin Support Palliat Care. 2012 Sep;6(3):379-85. doi: 10.1097/SPC.0b013e328356ab0c. PMID: 22801466. **-No original data**
Valery PC, Powell E, Moses N, et al. Systematic review: unmet supportive care needs in people diagnosed with chronic liver disease. BMJ Open. 2015 Apr 8;5(4):e007451. doi: 10.1136/bmjopen-2014-007451. PMID: 25854973. **- Not relevant to key questions**

Appendix C. Results

Search Results Part (a)

We reviewed 139 Web pages (Figure C-1) and included 46. Appendix B lists the excluded Web pages.

Figure C-1. Summary of the website search Part (a)

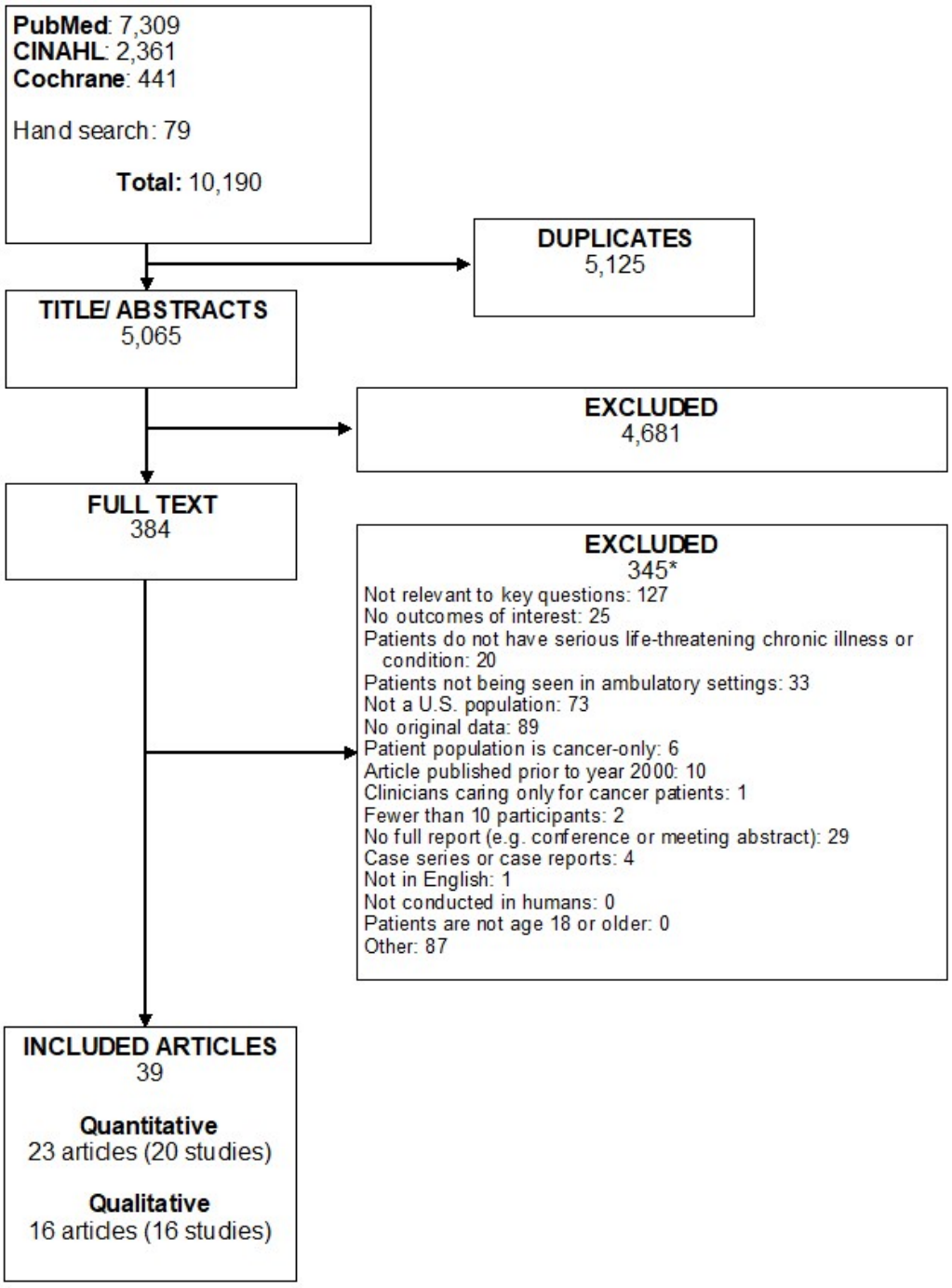


EPEC=Education in Palliative & End-of-life Care

Search Results Part (b) and Part (c)

We retrieved 5,065 unique citations (Figure C-2). After screening abstracts and full-text, we included 39 articles reporting 36 studies. Appendix B lists the excluded articles.

Figure C-2. Summary of the literature search Part (b) and Part (c)



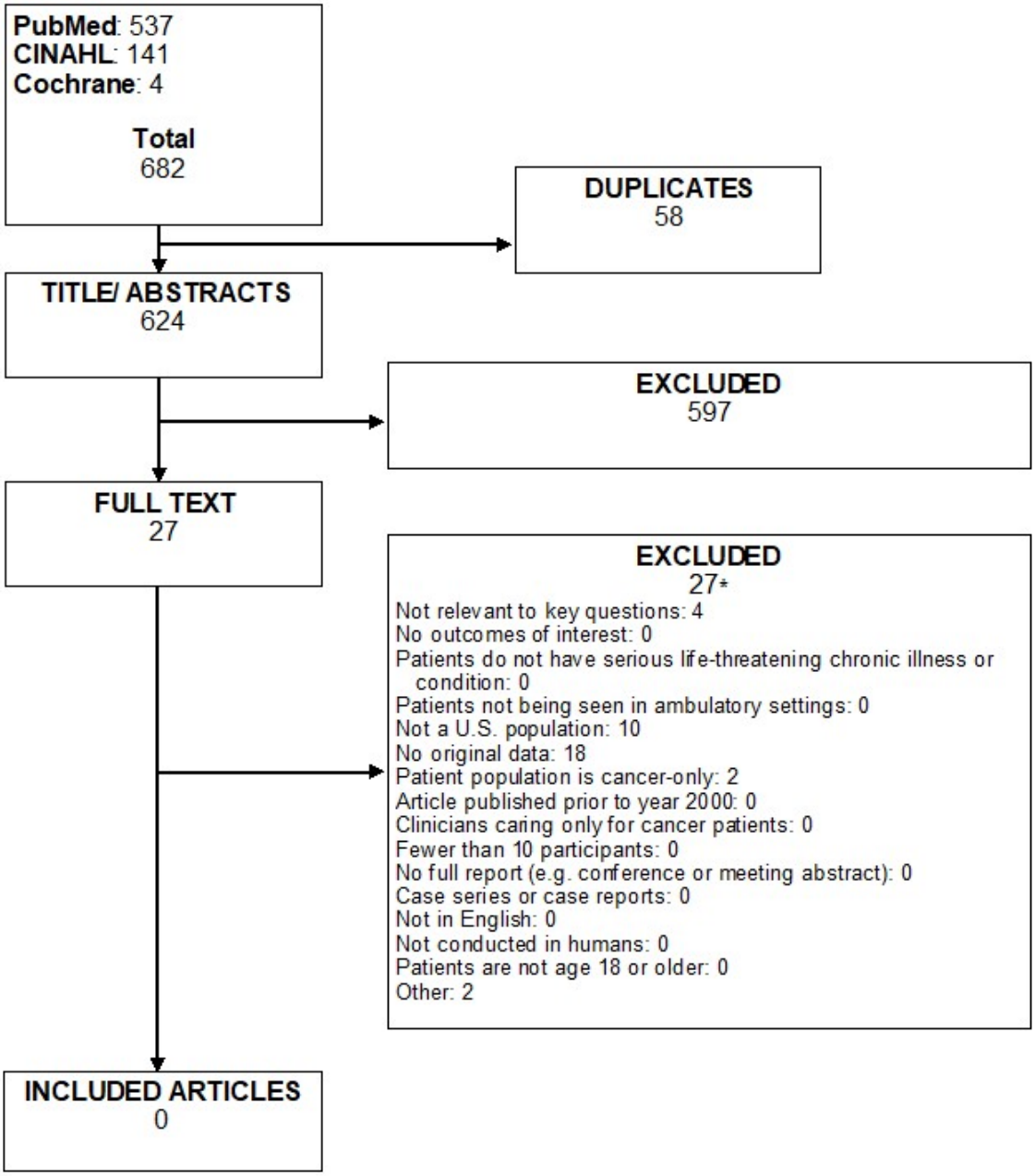
EPEC=Education in Palliative & End-of-life Care

* Sum of excluded articles exceeds 345 because reviewers were not required to agree on reasons for exclusion.

Search Results Part (c) Reviews

We retrieved 624 unique citations (Figure C-3). After screening abstracts and full-text, we included zero studies. Appendix B lists the excluded articles .

Figure C-3. Summary of the literature search Part (c) reviews



U.S.=United States

* Sum of excluded articles exceeds 27 because reviewers were not required to agree on reasons for exclusion.

Characteristics of Included Studies

These tables include study characteristics, inclusion and exclusion criteria, participant characteristics, intervention details, and details on outcomes. Additional details of included studies are found in Appendix D, Evidence Tables.

Included Web Pages

KQ1a: What prediction models, tools, triggers and guidelines and position statements are available about how to identify when and which patients with serious life-threatening chronic illness or conditions in ambulatory settings could benefit from palliative care?

Table C-1. Included Web Pages

Organizational Website	Web Resource
Alzheimer's Association	https://www.alz.org/media/Documents/end-of-life-care-statement.pdf
American Nephrology Nurses Association	https://www.annanurse.org/download/reference/health/position/palliativeCare.pdf
Center to Advance Palliative Care	https://www.capc.org/toolkits/patient-identification-and-assessment/
Hospice and Palliative Care Nurses Association	https://advancingexpertcare.org/position-statements
National Consensus Project for Quality Palliative Care	http://nchpc.conferencespot.org/67968-nchpc-1.4266595/t001-1.4266873/f001-1.4266874/a001-1.4266878
National Coalition for Hospice and Palliative Care	https://nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf
	https://nationalcoalitionhpc.us16.list-manage.com/subscribe?u=707e5c14e3dd0d0f687f12164&id=eaedc60374
World Health Organization	https://apps.who.int/iris/bitstream/handle/10665/274559/9789241514477-eng.pdf?ua=1

KQ2a. What educational materials and resources are available about palliative care and palliative care options for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers?

Table C-2. Included Web pages

Organizational Website	Web Resource
AARP	https://www.aarp.org/caregiving/health/info-2019/palliative-care.html
Alzheimer's Association	https://www.alz.org/help-support/i-have-alz/plan-for-your-future/end_of_life_planning
American Heart Association	https://www.heart.org/en/health-topics/heart-failure/living-with-heart-failure-and-managing-advanced-hf/planning-ahead-advanced-heart-failure
American Lung Association	https://www.lung.org/lung-health-and-diseases/lung-disease-lookup/copd/patient-resources-and-videos/
American Thoracic Society	https://www.thoracic.org/patients/patient-resources/resources/palliative-care.pdf
Center to Advance Palliative Care	https://getpalliativecare.org/about/
Coalition for Supportive Care of Kidney Patients	https://www.kidneysupportivecare.org/for-patients-families/advanced-care-planning/
HRSA	https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum
Kaiser Family Foundation	https://www.kff.org/medicare/fact-sheet/10-faqs-medicares-role-in-end-of-life-care/
National Institute of Nursing Research	https://www.ninr.nih.gov/sites/files/docs/palliative-care-brochure.pdf
	https://www.ninr.nih.gov/sites/files/docs/cuidadospaliativos.pdf
	https://www.ninr.nih.gov/newsandinformation/what-is-palliative-care
National Institute on Aging	https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives
	https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care
	https://www.nia.nih.gov/health/getting-your-affairs-order
	https://order.nia.nih.gov/publication/advance-care-planning
	https://www.nia.nih.gov/health/legal-and-financial-planning-people-alzheimers
National Kidney Foundation	https://www.kidney.org/atoz/content/palliative-care-helps-patients-kidney-disease

KQ3a. What palliative care shared decision-making tools are available for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers?

Table C-3. Included Web pages

Organizational Website	Web Resource
Alzheimer's Association	https://www.alz.org/help-support/i-have-alz/plan-for-your-future/end_of_life_planning
American Heart Association	https://www.heart.org/en/health-topics/heart-failure/living-with-heart-failure-and-managing-advanced-hf/planning-ahead-advanced-heart-failure
Coalition for Supportive Care of Kidney Patients	https://www.kidneysupportivecare.org/for-patients-families/advanced-care-planning/
National Institute on Aging	https://www.nia.nih.gov/health/advance-care-planning-healthcare-directives

KQ4a. What palliative care training and educational materials are available for non-palliative care clinicians caring for patients with serious life-threatening chronic illness or conditions in ambulatory settings?

Table C-4. Included Web pages

Organizational Website	Web Resource
Alzheimer's Association	https://www.alz.org/professionals/public-health/core-areas/educate-train-professionals
	https://www.alz.org/media/Documents/end-of-life-care-statement.pdf
American College of Physicians	https://www.acponline.org/cme-moc/online-learning-center/palliative-care-in-advance-heart-failure
American Nephrology Nurses Association	https://www.annanurse.org/download/reference/health/position/palliativeCare.pdf
American Nurses Association/Foundation	https://hope.film/study-guide-videos/
Center to Advance Palliative Care	https://www.capc.org/tools-for-making-the-case/downloadable-tools/
	https://www.capc.org/training/best-practices-in-dementia-care-and-caregiver-support/supporting-caregivers-people-living-dementia/
Coalition for Supportive Care of Kidney Patients	https://www.kidneysupportivecare.org/advanced-care-planning/
Hartford Foundation	https://www.johnahartford.org/dissemination-center/view/advance-care-planning-poll
Hospice and Palliative Care Nurses Association	https://advancingexpertcare.org/position-statements
HRSA	https://bhw.hrsa.gov/grants/geriatrics/alzheimers-curriculum
National Coalition for Hospice and Palliative Care	https://nationalcoalitionhpc.org/wp-content/uploads/2018/10/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf
Pew Charitable Trusts	https://www.pewtrusts.org/en/research-and-analysis/fact-sheets/2015/05/pew-glossary-improving-end-of-life-care
World Health Organization	https://apps.who.int/iris/bitstream/handle/10665/274559/9789241514477-eng.pdf?ua=1

KQ5a: What models (i.e., stepped care, consultative care, shared care, collaborative care, coaching, integrating social workers into practice, and palliative care approaches provided by non-palliative care specialists) and multimodal interventions for integrating palliative care have been developed for patients with serious life-threatening chronic illness or conditions in ambulatory settings?

Table C-5. Included Web pages

Organizational Website	Web Resource
Centers for Medicare & Medicaid Services	https://innovation.cms.gov/innovation-models/primary-care-first-model-options
National Academy of Science Roundtable on Quality of Care for People with Serious Illness	https://www.nationalacademies.org/our-work/models-and-strategies-to-integrate-palliative-care-principles-into-serious-illness-care-a-workshop

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Key Informant Key Points

Clinician/Stakeholder Key Informant Calls: December 4, 2019

KQ4c. How have palliative care training and educational materials (with or without other intervention components) **for non-palliative care clinicians** caring for patients with serious life-threatening chronic illness or conditions in ambulatory settings been implemented? What is the evidence for how, when, and for which clinicians they could best be implemented in care?

Table C-6. Clinician/stakeholder response to Key Question 4c

Concept	Summary of Responses
How, when and for which clinicians could they best be implemented?	Palliative care educational materials for clinicians and their effectiveness Questions about modality; who receives training; what trainings do they need; how does it work inside of training and education programs; how do we direct people to those things; which clinicians to focus on

KQ5c. What are components of models and multimodal interventions for integrating palliative care in ambulatory settings? What models and multimodal interventions have been implemented for key subpopulations? What components and characteristics of these models and multimodal interventions contribute to their effective implementation? What is the evidence for how, when, and for which patients they could best be implemented in care?

Table C-7. Clinician/stakeholder response to Key Question 5c

Concept	Summary of Patient/Caregiver Responses
Components of models	Communication should include discussing illness, understanding treatment options and decision making Domains from the National Consensus Project Guidelines for Palliative Care: Addressing symptoms, including pain as a holistic concept (including existential, emotional, social pain); psychosocial intervention addressing coping Understanding treatment options and risks, burdens and benefits Coordination of follow-up care/ community resources Primary care doctors should “quarterback” palliative care and push it out to the specialist teams Palliative care would best be aided by coordinating care to include pain management specialists, as well as social workers who can provide perspective
Implementation of models -how?	Introducing palliative care requires creating time and space to allow this to happen; primary teams need to be prepared and supported Integration into and simplifying workflow is key, making things easier for primary clinicians through coordination with community resources Key steps and mechanisms include identifying and selecting patients, leveraging systems (payment), documentation systems, connecting patients to community resources, quality measurement and quality improvement, delivery system design, coordinating with informatics systems, explicitly stating focus of intervention/ key outcomes Inter-professional perspectives and considering practice setting are key Exploring what matters most to patients, and what needs can we best meet and how with limited time and multiple priorities Consolidated Framework for Implementation Research most applicable
Implementation of models - when and for which patients?	Consider what type of population by both disease and socioeconomic status, as well as other characteristics. Individual steps: patient identification triggers/reminder systems Specific steps may look different based on primary care vs. other ambulatory (specialty) care

Patient/Caregiver Key Informant Calls: June 18, 2019 and November 20, 2019

KQ4c. How have palliative care training and educational materials (with or without other intervention components) **for non-palliative care clinicians** caring for patients with serious life-threatening chronic illness or conditions in ambulatory settings been implemented? What is the evidence for how, when, and for which clinicians they could best be implemented in care?

Table C-8. Patient/caregiver response to Key Question 4c

Concept	Summary of Patient/Caregiver Responses
How, when and for which clinicians could they best be implemented?	Communication: Patients often learn about palliative care on their own (e.g., in support groups, though work as a patient advocate, or through courses taken), if they are even aware that it exists Developing and providing educational tools to patients and their caregivers could help with communication, but in context of physicians communicating with patients Palliative care training would be helpful, especially to help clinicians obtain necessary listening skills

KQ5c. What are components of models and multimodal interventions for integrating palliative care in ambulatory settings? What models and multimodal interventions have been implemented for key subpopulations? What components and characteristics of these models and multimodal interventions contribute to their effective implementation? What is the evidence for how, when, and for which patients they could best be implemented in care?

Table C-9. Patient/caregiver response to Key Question 5c

Concept	Summary of Patient/Caregiver Responses
Components of models	Identifying patients by: Number of specialists they are in contact with and stated issues/conflicts with compliance or need for additional assistance for their care (e.g., medication costs/compliance, multiple physician appointments/follow-ups, etc.) Include caregivers in discussions and provide them with education
Implementation of models -how, when and for which patients?	Critical for clinicians to initiate discussions and clarify what palliative care is, how it is distinct from hospice, why it is important, and its goals (e.g., to increase quality of life and to be patient-centered) Clinicians should present all available options and be clear about the importance of patient/caregiver involvement in the process Communication about palliative care should occur early, be hands-on/face-to-face, and provide information in a patient-friendly, easily understandable manner and format, aided by educational materials (e.g., discussions, educational brochures, handbooks, etc.)

Website Review

We searched 139 U.S. webpages and identified the following Web resources: 9 about prediction models, tools, and triggers and 5 guidelines and position statements about identifying patients; 13 about educational materials and resources for patients and their caregivers; 5 about shared decision-making tools; 12 about training and educational materials for non-palliative care clinicians; and 2 about models and multimodal interventions for integrating palliative care (see Results Appendix for listing of websites searched). We found no evaluation or study about the effectiveness or implementation of models or multimodal interventions for integrating palliative care for any of the Web resources identified.

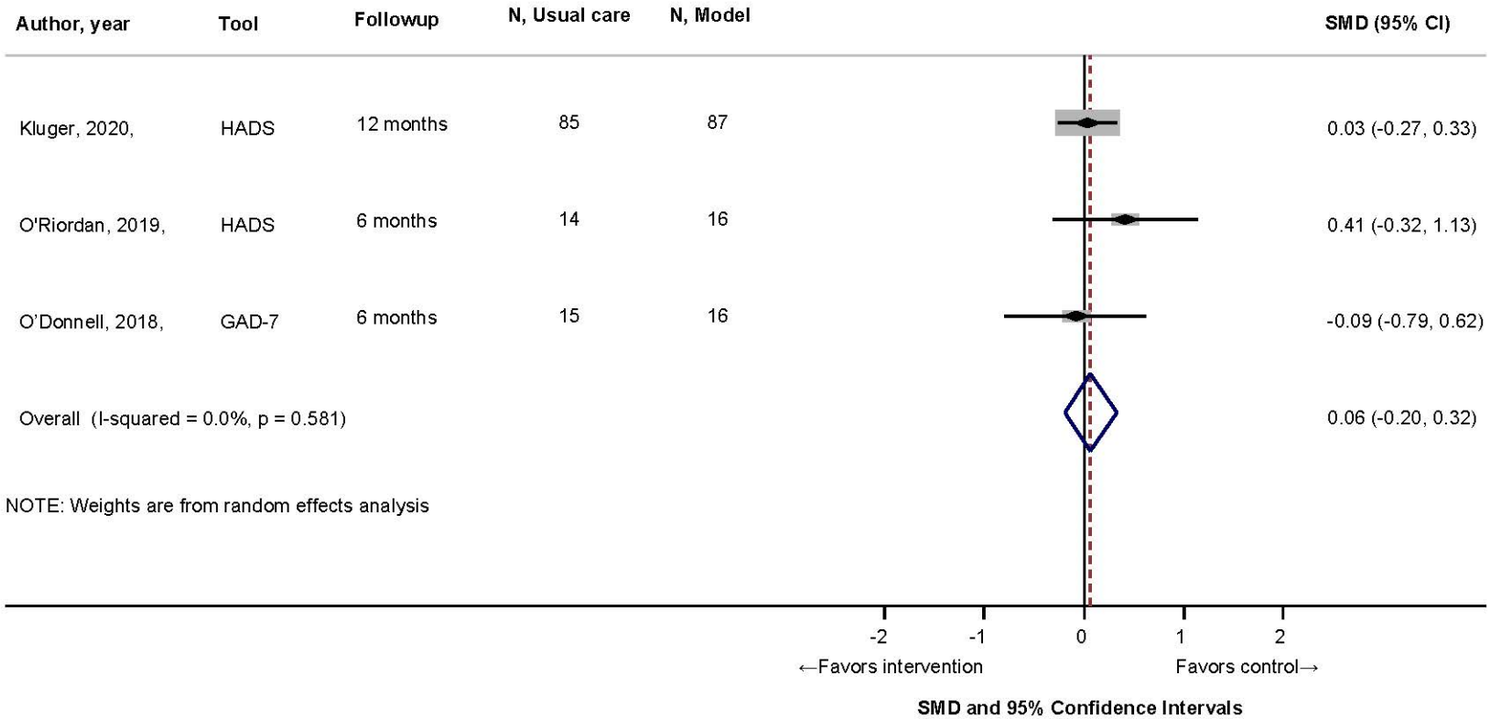
The websites with Web resources included the official sites of two palliative care organizations; three primary care and specialty healthcare professional organizations; three Federal government organizations; four national foundations, with a major focus in palliative care; and four patient organizations. More than half (n=24) of the resource content was focused on advance care planning and included downloadable information and links to other website resources. Patient educational materials and resources focused on palliative care definitions, information, and resources, as well as caregiver information; only one educational resource was available in a language other than English. Healthcare professional training and educational materials were in the form of videos, fact sheets, or modules in a curriculum.

All resources were free, except five resources that were on websites free only to members of the respective organizations. Four of those five exceptions were about prediction models, tools, triggers, and guidelines and position statements available for identification of patients in ambulatory settings who could benefit from palliative care. One of those five exceptions was about palliative care training and educational materials available for non-palliative care clinicians caring for patients with serious life-threatening chronic illness or conditions in ambulatory settings.

Meta-Analysis Figures

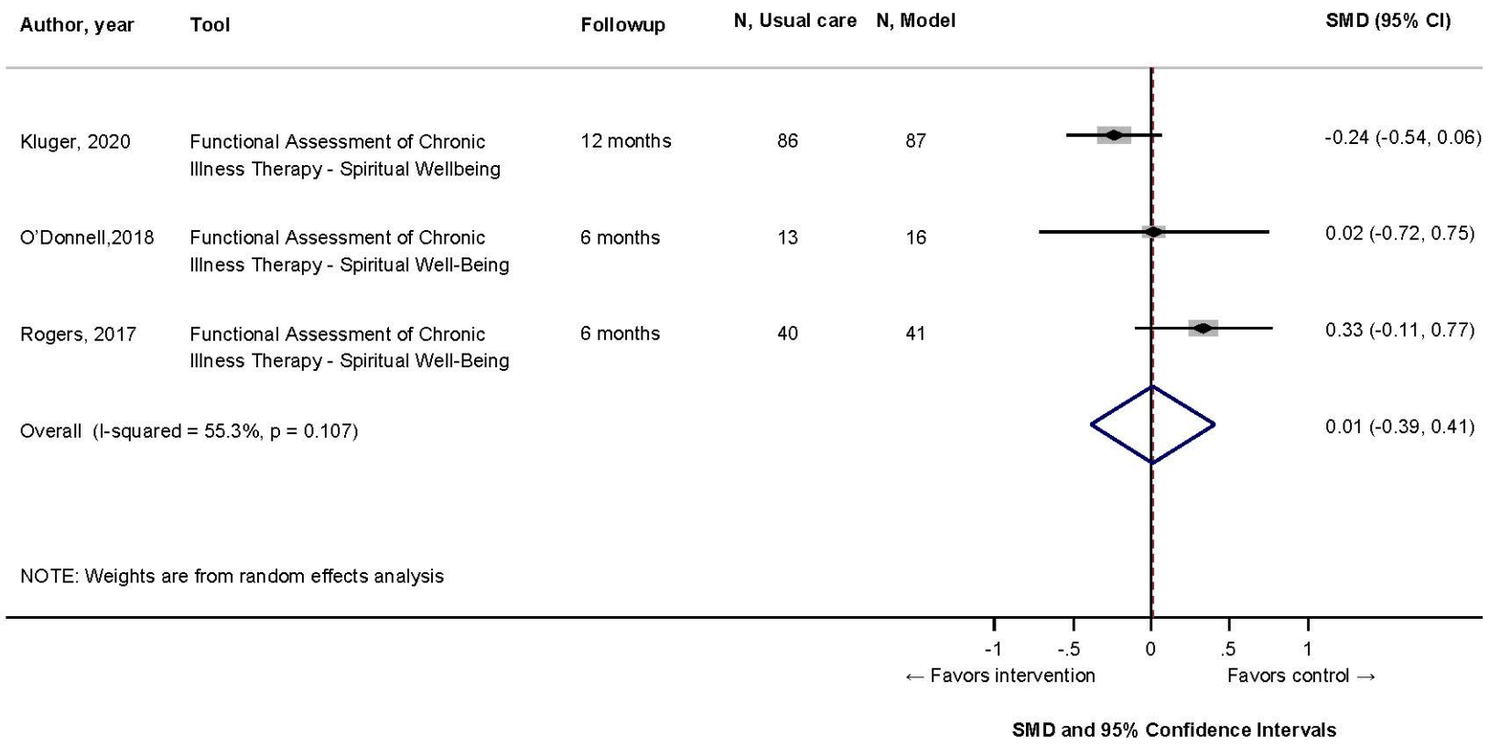
Key Question 5b: Meta-analysis of the effectiveness of models and multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Figure C-4. Meta-analysis of the effects of models for integrating palliative care on anxiety in patients with non-cancer serious chronic illness compared with usual care



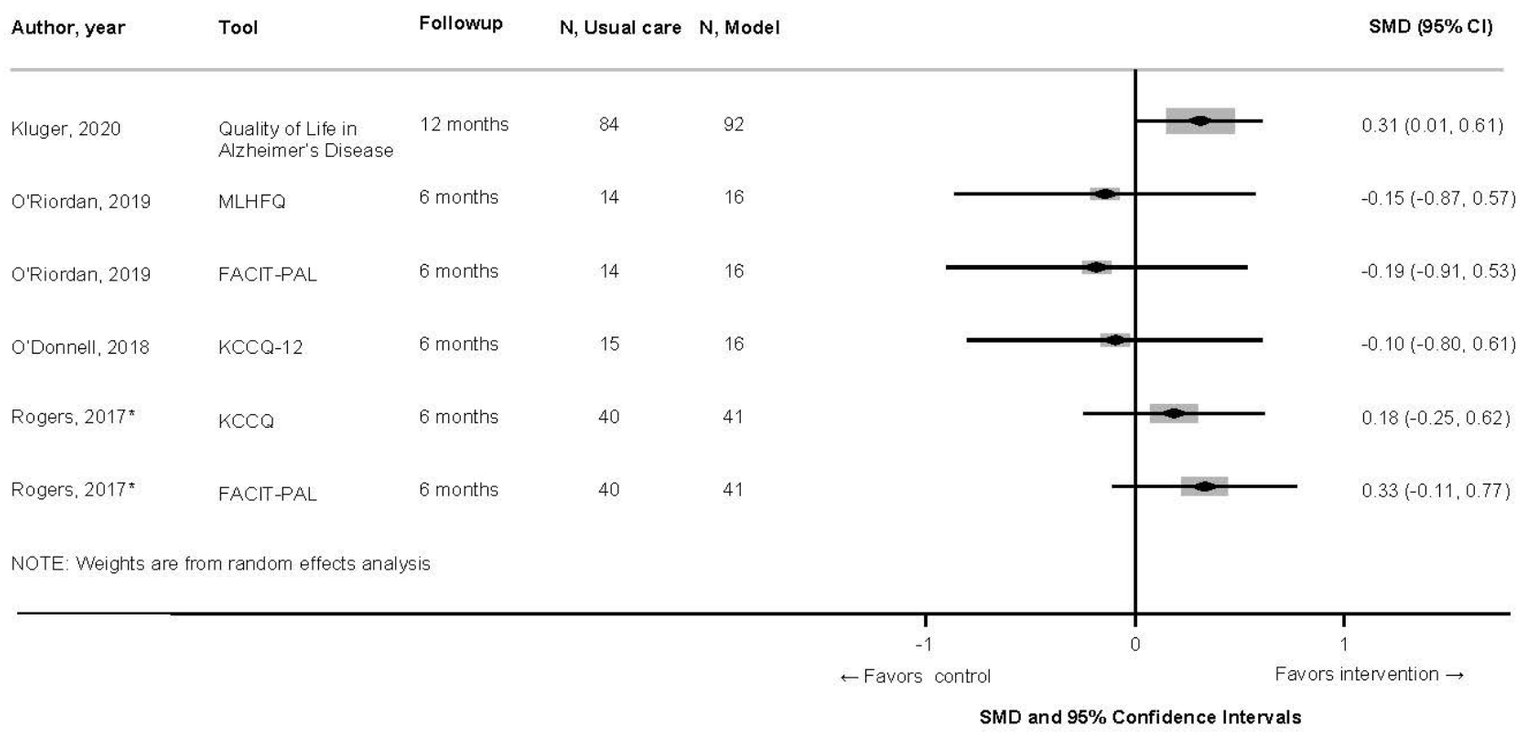
CI=confidence interval; GAD-7=General Anxiety Disorder-seven item; HADS= Hospital Anxiety and Depression Scale; N=sample size; SMD=standardized mean difference

Figure C-5. Meta-analysis of the effects of models for integrating palliative care on psychological well-being in patients with noncancer serious chronic illness compared with usual care



CI=confidence interval; N=sample size; SMD=standardized mean difference

Figure C-6. Forest plot of the effects of models for integrating palliative care on health-related quality of life in patients with non-cancer serious chronic illness compared with usual care



CI=confidence interval; FACIT-PAL=Functional Assessment of Chronic Illness Therapy - Palliative Care; KCCQ=Kansas City Cardiomyopathy Questionnaire; KCCQ-12=Kansas City Cardiomyopathy Questionnaire-12 item; MLHFQ=Minnesota Living with Heart Failure Questionnaire; N=sample size; SMD=standardized mean difference

*Rogers, 2017 et al.[1] standardized mean difference calculated using difference between baseline and outcome at 6 months.

Reference

1. Rogers JG, Patel CB, Mentz RJ, et al. Palliative Care in Heart Failure: The PAL-HF Randomized, Controlled Clinical Trial. J Am Coll Cardiol. 2017 Jul 18;70(3):331-41. doi: 10.1016/j.jacc.2017.05.030. PMID: 28705314.

Appendix D. Evidence Tables

Table D-1. Study design characteristics for studies comparing effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Author, Year Study Name	Study Design	Recruitment Years	Followup	Study Location	Study Setting	Palliative Care Services Already Available	Funding Source
Au, 2012[1] NR	RCT	2004 to 2007	2 weeks	Academic	Two Veterans Affairs (VA) facilities: a university-affiiated tertiary referral medical center and a predominantly nonteaching outpatient facility	Unclear	Government
Curtis, 2018[2] NR	RCT	2014 to 2016	6 months	Academic and community	Primary and specialty care	Unclear	PCORI (government) and private (Cambia Health Foundation)
Doorenbos, 2016[3] Goals of Care Intervention (GoC)	RCT	NR	2 weeks	Academic	Cardiology	Yes	Government and Non Profit
Kirchhoff, 2012[4] NR	RCT	NR	NR	Academic	ESRD and CHF clinics	Unclear	Government
Perry, 2005[5] NR	RCT	NR	4 months	Academic	Nephrology	Unclear	Government and Non profit
Song, 2009[6] Sharing Patients' Illness Representations to Increase Trust (SPIRIT)	RCT	NR	3 months	Academic	Nephrology	Unclear	Government

CHF=chronic heart failure; ESRD=end stage renal disease; GoC: Goals of Care Intervention; NR=not reported; PCORI= Patient-Centered Outcomes Research Institute; RCT=randomized controlled trial

Table D-2. Study design characteristics for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year Study Name	Study Design	Recruitment Years	Followup	Study Location	Study Setting	Palliative Care Services Already Available	Funding
Bekelman, 2015[7] NR	RCT	2009 to 2011	12 months	Unclear / Not reported, VAMCs	Primary care	Unclear	Government
Bekelman, 2018[8] CASA	RCT	2012 to 2015	6 months	Academic, VA, and safety net health systems	Unclear	Unclear	Grants from National Institute of Nursing Research, National Institutes of Health, National Institutes of Health/National Center for Advancing Translational Sciences Colorado Clinical and Translational Science Award, and Veterans Affairs Health Services Research and Development Service
Dionne-Odom, 2020[9] ENABLE CHF-PC	RCT	2015 to 2018	16 weeks	Academic	Academic tertiary care medical center and Veterans Affairs	Unclear	Government
Engelhardt, 2006[10] NR	RCT	Unclear	6 months	Unclear / Not reported	3 VAMCs, home care organization, 2 MCOs	Unclear	Non-profit
Engelhardt, 2009[11] NR	RCT	NR	NR	Unclear / Not reported	Unclear	Unclear	Non-profit and Kaiser Permanente
Feely, 2016[12] NR	Non-randomized studies with concurrent or historical controls	2011 to 2012	NR	Academic	Nephrology	No	NR
Goldstein, 2019[13] Working to improve discussions about defbrillator management (WISDOM)	RCT	2011 to 2016	24 months	Academic	Cardiology	Unclear	Not reported
Kluger, 2020[14] NR	RCT	2015 to 2017	12 months	Academic	Academic tertiary care medical center	Unclear	Non-profit
Lakin, 2017[15-17] NR	Non-randomized studies with concurrent or historical controls	2014 to 2015	NR	Academic	Primary care	Unclear	Nonprofit, Industry
O'Donnell, 2018[18] SWAP-HF	RCT	2014 to 2015	6 months	Academic	Inpatient/ambulatory	Yes	Private-E. G. Watkins Family Foundation

Author, Year Study Name	Study Design	Recruitment Years	Followup	Study Location	Study Setting	Palliative Care Services Already Available	Funding
O'Riordan, 2019[19] NR	RCT	2012 to 2013	6 months	Academic	Academic medical center	Unclear	Non-profit
Owens, 2012[20] NR	Non-randomized studies with concurrent or historical controls	2010 to 2010	NR	Academic	Primary Palliative Care Clinic	Yes	NR
Rabow, 2004[21, 22] NR	RCT	NR	1 year	Academic	Primary care	Unclear	Non-profit
Rogers, 2017[23] Palliative care in heart failure (PAL-HF)	RCT	2012 to 2015	6 months	Academic	Cardiology	Yes	Government

MCO=managed care organization; NR=not reported; RCT=randomized controlled trial; VAMC=Veteran's Affairs medical center

Table D-3. Study design Characteristics for qualitative studies implementing palliative care interventions for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Study Design	Recruitment Year	Followup	Study Location	Study Setting	Funding Source	Serious Illness Definition	Additional Aspects of Ambulatory Setting	Type of Healthcare System	Non-Palliative Care Services Available in Health Care Setting	Palliative Care Services Already Available
Bekelman, 2014[24] CASA	Qualitative or mixed-methods studies	2011 to 2012	3 months	Urban	One in-person visit with nurse (in outpatient center/inpatient when recruited); Telephone visits	Government	Not defined, but inclusion criteria included: Diagnosis of chronic HF, hospitalization in last year, >80mg furosemide, BNP >250, NT-pro BNP >1000	Hospital outpatient department	NR	NR	VA Medical Center & University hospital
Bekelman, 2016[25] NR	Qualitative	NR	NA	Non-Academic	Primary care, cardiology, ambulatory care, geriatrics, palliative care, mental health	Government	Not defined, but reference IOM: chronic illness resulting in frequent hospitalizations or death.	Multiple settings	Primary care, cardiology, ambulatory care, geriatrics, palliative care, mental health	NR	Verterans Health Administration

Author, Year	Study Design	Recruitment Year	Followup	Study Location	Study Setting	Funding Source	Serious Illness Definition	Additional Aspects of Ambulatory Setting	Type of Healthcare System	Non-Palliative Care Services Available in Health Care Setting	Palliative Care Services Already Available
Dillon, 2017[26] NR	Qualitative	2014 to 2015	NA	Non-Academic	Multispecialty group practice	HCSRN, OAIC Aging Initiative, NIA/NIH Grant, Palo Alto Medical Foundation, Richard and Susan Levy Family Trust	NCQA Definition: “Health condition that carries a high risk of mortality and either negatively impacts a person’s daily function or quality of life or excessively strains the caregiver.”	Multiple settings	Large, non-profit multispecialty group practice	Primary care, pulmonology, cardiogly, oncology departments	Not reported
Goff, 2019[27] SDM-RSC	Process evaluation studies (type of implementation studies)	2015 to 2017	NA	Academic	Nephrology	Multiple (specify)	Not defined	Nephrology	NR	NR	Academic
Hobler, 2018[28] NR	Integrated mixed-methods	NR	NA	Academic	Adult Cystic Fibrosis Center	Non-profit	Not defined - CF is a chronic disease with symptoms negatively impacting quality of life; disease involves complex treatment decisions	Other	Cystic fibrosis clinic	NR	Academic

Author, Year	Study Design	Recruitment Year	Followup	Study Location	Study Setting	Funding Source	Serious Illness Definition	Additional Aspects of Ambulatory Setting	Type of Healthcare System	Non-Palliative Care Services Available in Health Care Setting	Palliative Care Services Already Available
Lakin, 2019[29] NR	Qualitative	NR	NA	Academic	Primary care	Non-profit	Not defined	Primary care	NR	NR	Academic
Long, 2014[30] NR	Sequential mixed-methods	2013 to 2013	3 months	Non-Academic	Pulmonology	Hospice and Palliative Nurses Foundation via The American Nurses Foundation; one study team member funded by VA Career Development Award (HSR&D CDA08-022)	Not defined specifically - describes COPD as a debilitating, incurable, chronic illness	Pulmonology	NR	NR	Non-academic
Metzger, 2016[31] SPIRIT-HF	Qualitative	NR	NA	Academic	Cardiology	STTI/Hospice and Palliative Nurses Foundation End of Life Nursing Care Research Grant; NCATS/NIH (UL1TR001111); STTI Postdoc Award; NIH T32 (5T32NR007091)	Not defined	Cardiology	LVAD specialty clinic	NR	Academic

Author, Year	Study Design	Recruitment Year	Followup	Study Location	Study Setting	Funding Source	Serious Illness Definition	Additional Aspects of Ambulatory Setting	Type of Healthcare System	Non-Palliative Care Services Available in Health Care Setting	Palliative Care Services Already Available
Nowels, 2016[32] NR	Qualitative	2013 to 2016	NA	Unclear / Not reported	Primary care	Department of Medicine at University of Colorado	Chronically ill people with progressive illnesses and multiple morbidities	Primary care	NR	NR	Multiple: Community, academic-affiliated, academic medical center
Paladino, 2019[33] NR	Process evaluation studies (type of implementation studies)	2016 to 2018	NA	3 health care systems - Integrated healthcare system in TX, community hospital in MA, academic health care system in PA	Training appears to be conducted in respective healthcare settings (previously described)	Industry	Not defined	Multiple settings (specify)	Cardiology, radiation oncology, oncology, geriatrics, pediatrics, family medicine, primary care/internal medicine, palliative care, critical care/ICU, pulmonary, nephrology, other/unknown		Multiple types (described in study location section)
Rabow, 2003[34] Comprehensive Care Team (CCT)	Sequential mixed-methods	NR	1 Year	Academic	Primary care	Non-profit	Not defined	Primary care	NR	NR	Academic

Author, Year	Study Design	Recruitment Year	Followup	Study Location	Study Setting	Funding Source	Serious Illness Definition	Additional Aspects of Ambulatory Setting	Type of Healthcare System	Non-Palliative Care Services Available in Health Care Setting	Palliative Care Services Already Available
Scherer, 2018[35] NR	Qualitative	NR	NA	Academic	Nephrology	No funding received	Not specifically defined -- Discussed people with ESRD often have high mortality, poor quality of life, physical and emotional symptoms, and experience high healthcare utlization	Nephrology	NR	NR	Academic
Song, 2017[36] SPIRIT	Qualitative	2010 to 2014	NA	Academic	Nephrology	Government	Not defined	Nephrology	Dialysis clinic	NR	Academic
Uhler, 2015[37] NR	Qualitative	NR	NA	Non-Academic	Pulmonology	Government	Not specifically defined -- COPD is a progressive disease and 3rd leading cause of death in the United States; COPD exacerbations can cause symptoms to worsen, requiring hospitalization and advanced therapies (such as intubation)	Pulmonology	NR	NR	Public hospital-affiliated pulmonolgy clinic

BNP=brain natriuretic peptide; CF=cystic fibrosis; COPD= Chronic obstructive pulmonary disease; ESRD=end-stage renal disease; HCSRN=Health Care Systems Research Network; HF=heart failure; IOM=Institute of Medicine; LVAD= left ventricular assist device ; NA=not available; NCQA=National Committee for Quality Assurance; NIH=National Institutes of Health; NR=not reported; NT-pro BNP= NT-proB-type Natriuretic Peptide; OAIC=Older Americans Independence Center; VA=Veteran's Affair

Table D-4. Patient characteristics for studies comparing effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Author, Year	Arm #	Arm Name	Patient or Clinician as Participants	Sex, n (%)	Age	Race, n (%)	Advanced Heart Failure, n (%)	ESRD, n (%)	Advanced COPD, n (%)	Frailty, n (%)	Multiple Serious Chronic Conditions, n (%)
Au, 2012[1]	Arm 1	Control group	Patient	Male: 96.2 (NR) Female: NR	Mean: 69.6 (SD 10)	White: 87 (NR) African-American: NR Hispanic: NR Other: NR	NR (17.7)	NA	182 (100)	NR	NR
Au, 2012[1]	Arm 2	Intervention	Patient	Male: 97.9 (NR) Female: NR	Mean: 68.4 (SD 10)	White: 85.3 (NR) African-American: NR Hispanic: NR Other: NR	NR (12.8)	NA	194 (100)	NR	NR
Au, 2012[1]	Arm 1	Control group	Clinician	Male: 44 (NR) Female: NR	Mean: NR (SD NR)	White: 64.4 (NR) African-American: NR Hispanic: NR Other: NR	NA	NA	NA	NR	NR
Au, 2012[1]	Arm 2	Intervention	Clinician	Male: 50 (NR) Female: NR	Mean: NR (SD NR)	White: 87.5 (NR) African-American: NR Hispanic: NR Other: NR	NA	NA	NA	NR	NR
Curtis, 2018[2]	All	Overall	Patient	Male: 259 (52.4) Female: 235 (47.6)	Mean: 73.5 (SD 12.6)	NR	NR	NR	NR	NR	NR
Curtis, 2018[2]	All	Overall	Clinician	Male: 58 (46.8) Female: 66 (53.2)	Mean: 47.2 (SD 9.6)	NR	NR	NR	NR	NR	NR
Doorenbos, 2016[3]	Arm 1	Usual Care	Patient	**Male: 31 (79.5)** **Female: 8 (20.5)**	Mean: 56.21 (SD 11.93)	White: 33 (84.6) African-American: NR Hispanic: NR Other: NR	19 (48.7)	NA	NA	NA	NA
Doorenbos, 2016[3]	Arm 2	GoC	Patient	**Male: 30 (73.2)** **Female: 11 (26.8)**	Mean: 60 (SD 10.39)	White: 33 (80.5) African-American: NR Hispanic: NR Other: NR	15 (36.6)	NA	NA	NA	NA
Kirchhoff, 2012[4]	Arm 1	Usual care	Patient	NR	Mean: NR (SD NR)	NR	90 (NR)	64 (NR)	NA	NR	NR
Kirchhoff, 2012[4]	Arm 2	PC ACP	Patient	NR	Mean: NR (SD NR)	NR	90 (NR)	70 (NR)	NA	NR	NR

Author, Year	Arm #	Arm Name	Patient or Clinician as Participants	Sex, n (%)	Age	Race, n (%)	Advanced Heart Failure, n (%)	ESRD, n (%)	Advanced COPD, n (%)	Frailty, n (%)	Multiple Serious Chronic Conditions, n (%)
Perry, 2005[5]	Arm 1	Control	Patient	Male: NR Female: NR (54)	Mean: 44 (SD NR)	White: NR African-American: NR (39) Hispanic: NR Other: NR	NA	NA (100)	NA	NR	NR
Perry, 2005[5]	Arm 2	Printed materials	Patient	Male: NR Female: NR (46)	Mean: 44 (SD NR)	White: NR African-American: NR (39) Hispanic: NR Other: NR	NA	NA (100)	NA	NR	NR
Perry, 2005[5]	Arm 3	Peer Intervention	Patient	Male: NR Female: NR (46)	Mean: 45 (SD NR)	White: NR African-American: NR (37) Hispanic: NR Other: NR	NA	NA (100)	NA	NR	NR
Song, 2009[6]	Arm 1	Usual Care	Patient	Male: 14 (48.3) Female: NR	Mean: 57.55 (SD 12.2)	White: NA African-American: 29 (100) Hispanic: NA Other: NR	NA	29 (100)	NA	NR	NR
Song, 2009[6]	Arm 2	SPIRIT	Patient	Male: 19 (65.5) Female: NR	Mean: 58.31 (SD 11.8)	White: NA African-American: 29 (100) Hispanic: NA Other: NR	NA	29 (100)	NA	NR	NR
Song, 2009[6]	Arm 3	Usual Care	Caregiver	Male: 8 (27.6) Female: NR	Mean: 48.9 (SD 12.9)	White: 3 (10.3) African-American: NR Hispanic: NA Other: NR	NA	29 (100)	NA	NR	NR
Song, 2009[6]	Arm 4	SPIRIT	Caregiver	Male: 6 (20.7) Female: NR	Mean: 49.9 (SD 12.8)	NR	NA	29 (100)	NA	NR	NR

GoC=goals of care; n=sample size; NA=not available; NR=not reported; PC-ACP= Patient-Centered Advance Care Planning; SD=standard deviation; SPIRIT= Sharing Patients' Illness Representations to Increase Trust.

Table D-5. Patient characteristics for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm #	Arm Name	Patient or Clinician as Participants	Sex, n (%)	Age	Race, n (%)	Advanced Heart Failure, n (%)	ESRD, n (%)	Advanced COPD, n (%)	Frailty, n (%)	Multiple Serious Chronic Conditions, n (%)	Other Conditions, n (%)
Bekelman, 2015[7]	Arm 1	Usual care	Patient	Male: 193 (98) Female: 4 (2)	Mean: 67.9 (SD 10.6)	White: 165 (83.8) African-American: NR Hispanic: NR Other: NR	197 (100)	NR	59 (29.9)	NR	NR	NR
Bekelman, 2015[7]	Arm 2	Intervention	Patient	Male: 178 (95.2) Female: 9 (4.8)	Mean: 67.3 (SD 9.6)	White: 149 (79.7) African-American: NR Hispanic: NR Other: NR	187 (100)	NR	57 (30.5)	NR	NR	NR
Bekelman, 2018[8]	Arm 1	Usual care	Patient	Male: 119 (75.8) Female: 38 (24.2)	Mean: 66.5 (SD 11.8)	White: 115 (73.2) African-American: NR Hispanic: NR Other: NR	157 (100)	NR	NR	NR	NR	NR
Bekelman, 2018[8]	Arm 2	CASA	Patient	Male: 128 (81.5) Female: 29 (18.5)	Mean: 64.5 (SD 10.9)	White: 111 (70.7) African-American: NR Hispanic: NR Other: NR	157 (100)	NR	NR	NR	NR	NR
Dionne-Odom, 2020[9]	Arm 1	Usual Care	Caregiver	Male: 14 (18.4) Female: 62 (81.6)	Mean: 57.6 (SD 10.8)	White: 38 (50) African-American: 36 (47.4) Hispanic: NR Other: 2 (2.6)	NR	NR	NR	NR	NR	NR
Dionne-Odom, 2020[9]	Arm 2	Intervention	Caregiver	Male: 9 (11) Female: 73 (89)	Mean: 58.2 (SD 12.4)	White: 32 (39) African-American: 46 (56.1) Hispanic: NR Other: 3 (3.6)	NR	NR	NR	NR	NR	NR

Author, Year	Arm #	Arm Name	Patient or Clinician as Participants	Sex, n (%)	Age	Race, n (%)	Advanced Heart Failure, n (%)	ESRD, n (%)	Advanced COPD, n (%)	Frailty, n (%)	Multiple Serious Chronic Conditions, n (%)	Other Conditions, n (%)
Engelhardt, 2006[10]	Arm 1	Usual care	Patient	Male: 108 (76.1) Female: 34 (23.9)	Mean: 70.8 (SD NR)	White: 120 (85.7) African-American: 16 (11.4) Hispanic: NR Other: 4 (2.9)	21 (14.8)	NR	25 (17.6)	NR	NR	Cancer UC 94 (66.2), AICCP 84 (63.2): 2 (1.4)
Engelhardt, 2006[10]	Arm 2	AICCP	Patient	Male: 108 (81.2) Female: 25 (18.8)	Mean: 70.72 (SD NR)	White: 117 (88) African-American: 15 (11.3) Hispanic: NR Other: 1 (0.8)	22 (16.5)	NR	27 (20.3)	NR	NR	0 (0)
Engelhardt, 2009[11]	Arm 1	Usual Care	Patient	Male: 108 (52.7) Female: 97 (47.3)	Mean: 68.4 (SD 12.1)	White: 183 (91) African-American: NR Hispanic: NR Other: NR	39 (19)	44 (21.5)	41 (20)	NR	NR	Other is cancer patients: 81 (39.5)
Engelhardt, 2009[11]	Arm 2	AICCP	Patient	Male: 63 (31.8) Female: 135 (68.2)	Mean: 66 (SD 12.1)	White: 167 (84.8) African-American: NR Hispanic: NR Other: NR	30 (15.2)	46 (23.2)	36 (18.2)	NR	NR	Other is cancer patients: 86 (43.4)
Feely, 2016[12]	All	All	Patient	Male: 57 (62) Female: 35 (38)	Median: 68.5 Range: 27 to 95	White: 78 (84.8) African-American: NR Hispanic: NR Other: NR	NR	92 (100)	NR	NR	NR	NR
Goldstein, 2019[13]	Arm 1	Standard Care	Clinician	Male: 23 (48.9) Female: 24 (51.1)	NR	White: 38 (80.9) African-American: NR Hispanic: NR Other: NR	NA	NA	NA	NA	NA	NA
Goldstein, 2019[13]	Arm 2	WISDOM	Clinician	Male: 20 (41.7) Female: 28 (58.3)	NR	White: 38 (80.9) African-American: NR Hispanic: NR Other: NR	NA	NA	NA	NA	NA	NA

Author, Year	Arm #	Arm Name	Patient or Clinician as Participants	Sex, n (%)	Age	Race, n (%)	Advanced Heart Failure, n (%)	ESRD, n (%)	Advanced COPD, n (%)	Frailty, n (%)	Multiple Serious Chronic Conditions, n (%)	Other Conditions, n (%)
Goldstein, 2019[13]	Arm 1	Standard Care	Patient	Male: 165 (73.3) Female: 59 (26.7)	Mean: 64.3 (SD 12.6)	White: 97 (44.7) African-American: NR Hispanic: NR Other: NR	224 (100)	NR	NR	NR	NR	NR
Goldstein, 2019[13]	Arm 2	WISDOM	Patient	Male: 200 (67.3) Female: 101 (32.7)	Mean: 59.95 (SD 13.9)	White: 131 (46.3) African-American: NR Hispanic: NR Other: NR	301 (100)	NR	NR	NR	NR	NR
Kluger, 2020[14]	Arm 1	Standard Care	Patient	Male: 70 (67.3) Female: 34 (32.7)	Mean: 70.7 (SD 8)	White: 93 (89.4) African-American: 2 (1.9) Hispanic: 3 (2.9) Other: 9 (8.7)	NR	NR	NR	NR	NR	Dementia: 30 (28.9)
Kluger, 2020[14]	Arm 2	Palliative Care Intervention	Patient	Male: 65 (61.3) Female: 41 (38.7)	Mean: 69.5 (SD 8.3)	White: 100 (94.3) African-American: 1 (0.9) Hispanic: 3 (2.8) Other: 5 (4.8)	NR	NR	NR	NR	NR	Dementia: 32 (30.5)
Kluger, 2020[14]	Arm 1	Standard Care	Caregiver	Male: 22 (25) Female: 66 (75)	Mean: 66.4 (SD 11.1)	White: 77 (87.5) African-American: 1 (1.1) Hispanic: 3 (3.4) Other: 10 (11.4)	NR	NR	NR	NR	NR	NR
Kluger, 2020[14]	Arm 2	Palliative Care Intervention	Caregiver	Male: 25 (28.7) Female: 62 (71.3)	Mean: 65.7 (SD 11.7)	White: 82 (94.3) African-American: 0 (0) Hispanic: 5 (5.8) Other: 5 (5.7)	NR	NR	NR	NR	NR	NR

Author, Year	Arm #	Arm Name	Patient or Clinician as Participants	Sex, n (%)	Age	Race, n (%)	Advanced Heart Failure, n (%)	ESRD, n (%)	Advanced COPD, n (%)	Frailty, n (%)	Multiple Serious Chronic Conditions, n (%)	Other Conditions, n (%)
Lakin, 2017[15-17]	Arm 1	Comparison	Patient	Male: 35 (45.5) Female: 42 (54.5)	Mean: 78.5 (SD NR)	White: 61 (79.2) African-American: NR Hispanic: NR Other: NR	NR	NR	NR	NR	NR	NR
Lakin, 2017[15-17]	Arm 2	Integrated Care Program	Patient	Male: 55 (54.5) Female: 46 (45.5)	Mean: 79.5 (SD NR)	White: 82 (81.2) African-American: NR Hispanic: NR Other: NR	NR	NR	NR	NR	NR	NR
O'Donnell, 2018[18]	Arm 1	Usual care	Patient	Male: 15 (62.5) Female: 9 (37.5)	Mean: 69.2 (SD 10.2)	White: 20 (83.3) African-American: NR Hispanic: NR Other: 4 (16.7)	24 (100)	NR	NR	NR	NR	NR
O'Donnell, 2018[18]	Arm 2	Intervention	Patient	Male: 14 (53.9) Female: 12 (46.1)	Mean: 74.7 (SD 11.2)	White: 17 (65.4) African-American: NR Hispanic: NR Other: 9 (34.6)	26 (100)	NR	NR	NR	NR	NR
O'Riordan, 2019[19]	Arm 1	Usual Care	Patient	Male: 10 (72) Female: 4 (28)	Mean: 59 (SD 19)	White: 6 (43) African-American: NR Hispanic: NR Other: NR	NR	NR	NR	NR	NR	NR
O'Riordan, 2019[19]	Arm 2	PC Intervention	Patient	Male: 5 (31) Female: 11 (69)	Mean: 71 (SD 18)	White: 7 (44) African-American: NR Hispanic: NR Other: NR	NR	NR	NR	NR	NR	NR

Author, Year	Arm #	Arm Name	Patient or Clinician as Participants	Sex, n (%)	Age	Race, n (%)	Advanced Heart Failure, n (%)	ESRD, n (%)	Advanced COPD, n (%)	Frailty, n (%)	Multiple Serious Chronic Conditions, n (%)	Other Conditions, n (%)
Owens, 2012[20]	All	Overall	Patient	Male: 31 (63.3) Female: 18 (36.7)	Mean: 62 (SD 17.74) Median: 60 Range: 25 to 97	NR	NR	NR	NR	NR	NR	NR
Owens, 2012[20]	Arm 2	Not Cancer	Patient	Male: 19 (67.9) Female: 9 (32.1)	Mean: 64.96 (SD 19.71) Median: 60.5 Range: 31 to 97	NR	NR	NR	NR	NR	NR	NR
Rabow, 2004[21, 22]	Arm 1	Control	Patient	Male: 19 (47) Female: 21 (52)	Mean: 69.4 (SD 11.2)	White: 26 (65) African-American: NR Hispanic: NR Other: 14 (35)	14 (35)	NR	9 (22)	NR	NR	Other is cancer: 17 (42)
Rabow, 2004[21, 22]	Arm 2	Intervention	Patient	Male: 13 (26) Female: 37 (74)	Mean: 67.9 (SD 13.9)	White: 22 (44) African-American: NR Hispanic: NR Other: 28 (56)	17 (34)	NR	20 (40)	NR	NR	Other is cancer: 13 (26)
Rogers, 2017[23]	Arm 1	UC Alone	Patient	Male: 37 (49.3) Female: 38 (50.7)	Mean: 69.8 (SD 13.4)	White: 48 (64) African-American: 26 (34.7) Hispanic: NR Other: 0 (0)	5 (6.7)	NR	NR	NR	NR	NR
Rogers, 2017[23]	Arm 2	UC + PAL	Patient	Male: 42 (56) Female: 33 (44)	Mean: 71.9 (SD 12.4)	White: 38 (50.7) African-American: 36 (48) Hispanic: NR Other: 0 (0)	15 (20)	NR	NR	NR	NR	NR

AICCP= Advanced Illness Coordinated Care Program; CASA= Collaborative Care to Alleviate Symptoms and Adjust to Illness; n=sample size; NA=not available; NR=not reported;; PAL= palliative care intervention; PC=palliative care; SD=standard deviation; UC=usual care; WISDOM= Working to Improve discuSsions About DefibrillatOr Management.

Table D-6. Participant characteristics for qualitative studies implementing palliative care interventions for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Patient or Clinician as Participants	Clinician Training Specialty	Number at Baseline	Sex	Age	Race	Advanced Heart Failure	ESRD	Advanced COPD	Multiple Serious Chronic Conditions	Other
Dillon, 2017[26]	Clinician	MD, NP Non-palliative care	13 providers	NR	NR	NR	2 cardiologists, 1 cardiology NP (23)		3 pulmonologists (23)		4 oncologists (31), 3 PCPs (23)
Nowels, 2016[32]	Clinician	PA, NP Non-palliative care	20 providers	NR	NR	NR	NR	NR	NR	20 (100)	NR
Scherer, 2018[35]	Clinician	RN, office front staff, PC NP, hospitalist, NP, HF physician, fellow, administrative support staff Multiple	11 people on Kidney Palliative Care Advisory Group	NR	NR	NR	NR	NR	NR	NR	NR

Author, Year	Patient or Clinician as Participants	Clinician Training Specialty	Number at Baseline	Sex	Age	Race	Advanced Heart Failure	ESRD	Advanced COPD	Multiple Serious Chronic Conditions	Other
Uhler, 2015[37]	Both	MD Non-palliative care	Phase 1: 11 patients; Phase 2: 4 patients, 8 Doctors	Male: Phase 1 Patients: 6 (55); Phase 2 Patients: 3 (75) Female: Phase 1 Patients: 5 (45); Phase 2 Patients: 1 (25)	Mean: NR (SD NR) Median: Phase 1 Patients: 60; Phase 2 Patients: 72; Phase 2 Physicians: 33 Range: Phase 1 patients: 23-73; Phase 2 patients: 57-7; Phase 2 Physicians: 28-43	White: Phase 1 Patients: 0 (0); Phase 2 Patients: 2 (50); Phase 2 Physicians: 3 (38) African-American: Phase 1 Patients: 3 (27); Phase 2 Patients:2 (50); Phase 2 Physicians: 0 (0) Hispanic: Phase 1 Patients: 7 (64); Phase 2 Patients: 0 (0); Phase 2 Physicians: 0 (0) Other: Asian American: Phase 1 Patients: 1 (9); Phase 2 Patients: 0 (0); Phase 2 Physicans: 4 (50)	NR	NR	All pulmonologists; All patients had COPD (100)	NR	NR
Paladino, 2019[33]	Clinician	MD, APP, RN, other/unknown Multiple	297	NR	NR	NR	NR	NR	NR	NR	NR

Author, Year	Patient or Clinician as Participants	Clinician Training Specialty	Number at Baseline	Sex	Age	Race	Advanced Heart Failure	ESRD	Advanced COPD	Multiple Serious Chronic Conditions	Other
Bekelman, 2014[24]	Patient NA	NA	17	Male: 17 (100) Female: 0 (0)	Mean: 63 (SD NR) Median: NR Range: IQR: 58-71	White: 10 (58) African-American: NR Hispanic: NR Other: NR	NYHA III/IV: 7 (41.2)	NR	4 (23.5)	NR	Hypertension: 12 (70.6)
Bekelman, 2016[25]	Clinician	Nurse, social worker, PCP, cardiology physicians and APP, chiefs of service, regional and national leadership Non-palliative care	17	NR	NR	NR	Cardiology clinicians: 3 (17.64)	NR	NR	NR	Chiefs of service: 7; Regional/national leadership: 3; Primary care staff: 2
Lakin, 2019[29]	Clinician	Other Non-palliative care	14 clinicians	Male: Physicians: 3 (50); Nurse: 1 (16.6); Social work: 0 (0) Female: Physicians: 3 (50); Nurse: 5 (83.3); Social work: 2 (100)	NR	NR	NR	NR	NR	NR	Primary care (100)
Hobler, 2018[28]	Patient NA	NA	48 patients	Male: 24 Female: 24	Mean: 38 (SD 11) Median: NR Range: NR	White: 43 (94) African-American: NR Hispanic: NR Other: 3 (7)	NR	NR	NR	NR	Cystic fibrosis: 48 (100)

Author, Year	Patient or Clinician as Participants	Clinician Training Specialty	Number at Baseline	Sex	Age	Race	Advanced Heart Failure	ESRD	Advanced COPD	Multiple Serious Chronic Conditions	Other
Long, 2014[38]	Patient	NA NA	13	NR	NR	NR	NR	NR	13 (100)	NR	NR
Rabow, 2003[34]	Patient	NA NA	35 patients	NR	NR	NR	NR	NR	NR	NR	NR
Metzger, 2016[31]	Patient	NA NA	28 (14 patients 14 surrogates)	Male: Patients: 11 (78.6); Surrogate: 2 (14.3) Female: Patient: 3 (21.4); Surrogate: 12 (85.7)	Mean: Patient: 62.6; Surrogate: 56.2 (SD Patient: 7.6; Surrogate: 12.4) Median: NR Range: Patients: 44-74; Surrogates: NR	White: Patient: 4 (28.6); Surrogate: 4 (28.6) African-American: Patient: 10 (71.4); Surrogate: 10 (71.4) Hispanic: NR Other: NR	14 (100)	NA	NR	NR	NR
Goff, 2019[27]	Both	Social work, nephrology Non-palliative care	NR	NR	NR	NR	NR	NR	NR	NR	NR
Song, 2017[36]			24 bereaved surrogates of dialysis patients	Male: 7 Female: 17	Mean: 59 (SD 14) Median: NR Range: NR	White: 13 (54.2) African-American: 11 (45.8) Hispanic: Other:	NR	NR	NR	NR	NR

APP= American Physician Partners; COPD=chronic obstructive pulmonary disease; ESRD=end stage renal disease; HF=heart failure; IQR=interquartile range; MD= Doctor of Medicine; NA=not available; NP=nurse practitioner; NR=not reported; NYHA III= New York Heart Association Class III; NYHA IV= New York Heart Association Class IV; PA=physician assistant; PC NP=palliative care nurse practitioner; PCP=palliative care physician; RN=registered nurse; SD=standard deviation

Table D-7. Interventions for studies comparing effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Author, Year	Arm #	Arm Name	Training Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsession	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Au, 2012[1]	Arm 1	Control group	NR	NR	NR	NR	NR	NR	NR	NR	NR
Au, 2012[1]	Arm 2	Intervention	PT-specific feedback form	One-page PT-specific feedback form sent to pts, given to clinicians ahead of usual care visit; then shared at usual care visit	In person	Goals of care discussion / ACP	Prior to usual care visit, and at usual care visit	NR	2 weeks	MD, APN, PA	Non-palliative care
Curtis, 2018[2]	Arm 1	Usual care	NR	NR	NR	NR	NR	NR	NR	NR	NR
Curtis, 2018[2]	Arm 2	Jumpstart-Tips	Collaborative care	Prime clinicians and patients for a brief discussion of goals of care during a routine clinic visit	Email or fax	Goals of care discussion / ACP	Once	NR	NR	NR	NR
Doorenbos, 2016[3]	Arm 1	Usual Care	Usual care	NR	NR	NR	NR	NR	NR	NR	NR

Author, Year	Arm #	Arm Name	Training Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsession	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Doorenbos, 2016[3] (continued)	Arm 2	GoC	Coaching	Pre-visit coaching, PID barriers and facilitators to communication with provider, HF edu, px preference for communication about eol, completion of ad, 1 page activation/skills enhancement and role playing conversations. HF provider received activation sheet online prior to visit, outcomes of coaching and communication tips. Shared decision making: Education - patient preferences for communication about end-of-life care, and completion of the Five Wishes advance directive form, role playing. HF-provider received patient's desire for involvement in shared decision making.	Patient-telephone, provider-online	Goals of care discussion / ACP	1 time	NR	2 weeks	RN	Non-palliative care

Author, Year	Arm #	Arm Name	Training Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsession	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Kirchhoff, 2012[4]	Arm 1	Usual care	Palliative care approaches provided by non-palliative care specialists	Usual Care	In person	Goals of care discussion / ACP	1 hour	NR	NR	Nurses, social workers, and chaplains	Non-palliative care
Kirchhoff, 2012[4]	Arm 2	Intervention	Palliative care approaches provided by non-palliative care specialists	PC-ACP	In person	Goals of care discussion / ACP	1 hour	1 hour	90 hours	Nurses, social workers, and chaplains	Non-palliative care
Perry, 2005[5]	Arm 1	Control	None	Control	None	None	None	NR	NR	None	Palliative care
Perry, 2005[5]	Arm 2	Printed Materials	Intergrating printed materials into non palliative care	Printed materials	In person	Goals of care discussion / ACP, Printed material	Mid point of intervention, 2-4 months	NR	NR	Social Work(er)	NR
Perry, 2005[5]	Arm 3	Peer Intervention	Palliative care approaches provided by non-palliative care specialists	Peer group ACP AD intervention	In person	Goals of care discussion / ACP	5 telephone contacts and 3 face-to-face meetings over a 2-4 month contact period.	NR	2 - 4 months	Peer to peer	NR

Author, Year	Arm #	Arm Name	Training Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsession	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Song, 2009[6]	Arm 1	Usual Care	NR	A social worker at each dialysis clinic provided written information on advance directives and the patient's right to have an advance directive to every patient on the first day of dialysis treatment	In person	NR	NR	NR	One-time service provided on admission	SW	NR
Song, 2009[6]	Arm 2	SPIRIT	Palliative care approaches provided by non-palliative care specialists	Spirit Shared Decision Making Tool	In person	Goals of care discussion / ACP	Baseline TP 1, TP 2-one week, Tp 3-months	NR	3 months	RN, SW	Non-palliative care

ACP AD= advance care planning advance directives; ACP=advance care planning; APN=advanced practice nurse; HF=heart failure; MD=Doctor of Medicine; NR=not reported; PA=physician assistant; PC-ACP= Patient-Centered Advance Care Planning; pg=page; PT=physical therapy; Px=prognosis; RN=registered nurse; SPIRIT=Sharing Patients' Illness Representations to Increase Trust; SW=social worker; TP=timepoint.

Table D-8. Interventions for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm #	Arm Name	Model Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsessio n	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Bekelman, 2015[7]	Arm 1	Usual care	NR	Continual care from primary care clinician and regular telehealth nurses if patient had previously enrolled, given information sheet during enrolment on self-management of heart failure, depression diagnosis provided to primary care clinician.	NR	NR	NR	NR	NR	Primary care clinician, telehealth nurses	NR
Bekelman, 2015[7]	Arm 2	Intervention	Palliative Care Models: collaborative care	Palliative Care Models: Patient Centered Disease Management	Palliative Care Models: telephone	Palliative Care Models: symptom assessment	NR	NR	NR	Palliative Care Models: RN, PCP, cardiologist, psychiatrist	Palliative Care Models: Non-palliative care

Author, Year	Arm #	Arm Name	Model Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsessio n	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Bekelman, 2018[8]	Arm 1	Usual care	NR	As needed, unstructured symptoms assessment and management by primary care physician or nurse practitioner, referral to social worker for psychosocial assessment and management as needed, subject also received information sheet on self-care for heart failure.	NR	NR	As needed	As needed	NR	Primary care physician or nurse practitioner, referral to social worker	NR

Author, Year	Arm #	Arm Name	Model Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsession	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Bekelman, 2018[8]	Arm 2	CASA	Training/Education: palliative care approaches provided by non-palliative care specialists Palliative Care Models: collaborative care Multicomponent Interventions: palliative care approaches provided by non-palliative care specialists	Training/Education: nurse was trained in helping communication (1 hour), motivational interviewing (4 hours), and the symptom guidelines (3 hours), social worker received 8 hours of psychosocial intervention training and followup supervision Palliative Care Models: The nurse and social worker discussed patients in weekly collaborative care team meetings with a primary care clinician, a cardiologist, and a palliative care physician. Based on review of patients' medical records and discussion with the nurse and social worker, the team recommended medications and tests for the patients' usual care clinicians to review and give final approval.	Training/Education: in person Palliative Care Models: in person Multicomponent Interventions: telephone	Training/Education: communication, motivational interview, and symptom guidelines, psychosocial support Palliative Care Models: multiple Multicomponent Interventions: multiple	Training/Education: NR Palliative Care Models: Weekly Multicomponent Interventions: psychosocial, symptom assessment	Training/Education: NR Palliative Care Models: NR Multicomponent Interventions: 1-2 montly	Training/Education: 8 hours (nurse) + 8 hours (social worker) Palliative Care Models: NR Multicomponent Interventions: NR	Training/Education: NR Palliative Care Models: Social work, nurse, PCP, cardiologist, palliative care physician Multicomponent Interventions: 6 sessions for nurse intervention	Training/Education: NR Palliative Care Models: NR Multicomponent Interventions: Nurse, social worker

Author, Year	Arm #	Arm Name	Model Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsession	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Bekelman, 2018[8] (continued)	Arm 2	CASA	(continued)	(continued) Multicomponent Interventions: nurse intervention followup assessments by telephone (1-2 per month) were planned using a structured symptom rating scale, social worker provided a structured telephone-based psychosocial intervention to help patients with heart failure adjust to living with illness and address depression symptoms, if present	(continued)	(continued)	(continued)	(continued)	(continued)	(continued)	(continued)
Dionne-Odom, 2020[9]	Arm 1	Usual Care	NR	NR	NR	NR	NR	NR	NR	NR	NR
Dionne-Odom, 2020[9]	Arm 2	Intervention	Coaching	Four weekly psychosocial and problem-solving support telephonic sessions lasting between 20 and 60 minutes facilitated by a trained nurse coach plus monthly followup for 48 weeks.	Telephone	Psychosocial support	1 x per week	20-60 mins	4 weeks	RN	Non-palliative care

Author, Year	Arm #	Arm Name	Model Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsession	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Engelhardt, 2006[10]	Arm 1	Usual care	Usual care (not described)	Usual care (not described)	NR	NR	NR	NR	NR	NR	NR
Engelhardt, 2006[10]	Arm 2	AICCP	Training/Education: integrating care coordinators into practice Palliative Care Models: integrating care coordinators into practice	Training/Education: Advanced Illness Coordinated Care Program (AICCP) Palliative Care Models: Advanced Illness Coordinated Care Program (AICCP)	Training/Education: in person Palliative Care Models: in person	Training/Education: goals of care discussion NACP, psychosocial assessment Palliative Care Models: goals of care discussion NACP, psychosocial assessment	NR	NR	Training/Education: 6 sessions Palliative Care Models: 6 sessions	Training/Education: RN and SW Palliative Care Models: RN and SW	Training/Education: Non-palliative care Palliative Care Models: Non-palliative care
Engelhardt, 2009[11]	All	Overall	Palliative Care Models: integrating social workers into practice	Palliative Care Models: Advanced Illness Coordinated Care Program focused on nondirective health counseling, education and care coordination	Palliative Care Models: in person and telephone	Palliative Care Models: goals of care discussion NACP, psychosocial assessment	Palliative Care Models: average 4.9 (SD 2.1) sessions	Palliative Care Models: Mean 59 minutes (SD 22.1)	Palliative Care Models: max: 10 sessions	Palliative Care Models: SW and health educator	Palliative Care Models: Non-palliative care
Feely, 2016[12]	All	All	Palliative Care Models: shared care	Palliative Care Models: specialty palliative medicine physicians provide consultation to every patient on a hemodialysis unit	Palliative Care Models: in person	Palliative Care Models: goals of care discussion, symptom assessment	NR	NR	NR	Palliative Care Models: MD	Palliative Care Models: Palliative care

Author, Year	Arm #	Arm Name	Model Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsession	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Goldstein, 2019[13]	Arm 1	Usual care	NR	No clinician training was provided but had discussions regarding deactivation	NR	NR	NR	NR	NR	NR	NR
Goldstein, 2019[13]	Arm 2	WISDOM	Training/Education: coaching	Training/Education: Interactive skills training session on 1) advance care planning, with a focus on ICD deactivation and goals of care; and 2) automated electronic reminders to clinicians. The training comprised: 1) a discussion of barriers to initiating goals of care conversations in HF; 2) a video of an idealized advance care planning conversation; and 3) examples of specific techniques to improve communication	Training/Education: other	Training/Education: goals of care discussion / ACP	NR	Training/Education: 90 minutes	NR	Training/Education: Other	Training/Education: NR

Author, Year	Arm #	Arm Name	Model Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsessio n	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Kluger, 2020[14]	Arm 1	Standard Care	Standard care	Standard care	NR	NR	NR	NR	NR	NR	NR
Kluger, 2020[14]	Arm 2	Palliative Care Intervention	Palliative care approaches provided by both palliative and non-palliative care specialists, variation in the use of palliative medicine physician across sites	Standard care provided by the patient's primary care physician and a neurologist with additional outpatient palliative care led by a team of palliative neurologists with informal training in PC (eg, education through a palliative and end-of-life care workshop); a nurse, social worker, and chaplain with PD experience; and a board certified palliative medicine physician	Telephone or in-person	Goals of care discussions, psychosocial support and symptom management	Every 3 months	2-2.5 hours	1 year	MD, RN, social worker	Non-palliative care

Author, Year	Arm #	Arm Name	Model Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsession	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Lakin, 2017[15-17]	Arm 1	Usual care	Usual care (not described)	Usual care (not described)	NR	NR	NR	NR	NR	NR	NR
Lakin, 2017[15-17]	Arm 2	Integrated Care Program	Training/Education: coaching Triggers: coaching	Training/Education: structured teaching by palliative care experts including demonstration and practice with trained medical actors followed by monthly calls and as requested via ph one, email or in person Triggers: Use of the Surprise Question at 2 years	Training/Education: in person, phone, email Triggers: online	Training/Education: goals of care discussion / ACP Triggers: goals of care discussion / ACP	Training/Education: monthly Triggers: NR	NR	NR	Training/Education: Other Triggers: Other	Training/Education: Palliative care Triggers: Non-palliative care

Author, Year	Arm #	Arm Name	Model Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsessio n	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
O'Donnell, 2018[18]	Arm 1	Usual care	NR	Usual care on advanced care planning and quality of life with patient with heart failure who are at risk for mortality	NR	NR	NR	NR	NR	NR	NR
O'Donnell, 2018[18]	Arm 2	Social worker-led palliative care	Palliative Care Models: integrating social workers into practice	Palliative Care Models: Social worker–led intervention guided by Serious Illness Conversation Guide and included a structured evaluation of prognostic understanding, end-of-life preferences, symptom burden, and quality of life with routine review by a palliative care physician	Palliative Care Models: in person or telephone	Palliative Care Models: goal of care discussion NACP and symptom assessment	NR	NR	Palliative Care Models: During index hospital stay or first post-discharge followup	Palliative Care Models: Social Work(er)	Palliative Care Models: Non-palliative care

Author, Year	Arm #	Arm Name	Model Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsessio n	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
O'Riordan, 2019[19]	Arm 1	Usual Care	Usual Care	NR	NR	NR	NR	NR	NR	NR	NR
O'Riordan, 2019[19]	Arm 2	PC Intervention	Consultative care	Patients received intensive PC consultations provided by an interdisciplinary PC team (nurse practitioner, physician, social worker, and chaplain). Care included prescribing medications for symptoms, discussing advance care planning, completing appropriate documentation, and providing psychosocial and spiritual support.	Telephone or in-person	symptom assessment, goals of care and psychosocial support	Initially one week, then monthly	NR	6 months	NP, MD, social worker, chaplain	Palliative care
Owens, 2013[19]	All	Overall	Palliative Care Models: primary palliative care	Palliative Care Models: palliative care NP run primary care/palliative care clinic	Palliative Care Models: in person and telephone	Palliative Care Models: other	NR	NR	NR	Palliative Care Models: RN and NP	Palliative Care Models: Palliative car

Author, Year	Arm #	Arm Name	Model Type	Description of Intervention	Mode of Administration	Intervention Components	Frequency (Time Period)	Duration perSsession	Total Length of Intervention	Who Delivered Discipline	Who Delivered Dpecialty
Rabow, 2004[21, 22]	All	Overall	Training/Education: shared care Palliative Care Models: shared care	Training/Education: Comprehensive Care Team Palliative Care Models: Comprehensive Care Team	Training/Education: in person Palliative Care Models: in person, telephone, email	Training/Education: psychosocial support Palliative Care Models: goals of care discussioNACP, symptom assessment, psychosocial assessment	NR	NR	Training/Education: NR Palliative Care Models: 1 year	Training/Education: RN Palliative Care Models: MD, RN, SW, PharmD, chaplain, psychologist, art therapist, volunteer coordinaton	Training/Education: Palliative care Palliative Care Models: Palliative care
Rogers, 2017[23]	Arm 1	Usual care	NR	Cardiology-directed team with focus on symptom relief and evidence-based therapies based on current guidelines.	NR	NR	NR	NR	NR	NR	NR
Rogers, 2017[23]	Arm 2	Intervention	Palliative Care Models: collaborative care	Palliative Care Models: interdisciplinary, guideline driven, multicomponent; certified PC NP in collaboration with certified PC MD	Palliative Care Models: in person, phone	Palliative Care Models: goal setting, sx management, psychosocial support	Palliative Care Models: unclear	Palliative Care Models: unclear	Palliative Care Models: 6 months	Palliative Care Models: NP, MD	Palliative Care Models: Palliative care

ACP=advanced care program; AICCP=Advanced Illness Coordinated Care Program; CASA=Collaborative Care to Alleviate Symptoms and Adjust to Illness; HF=heart failure; ICD=International Statistical Classification of Diseases and Related Health Problems; MD=Doctor of Medicine; NP=nurse practitioner; NR=not reported; PC MD=palliative care Doctor of Medicine; PC NP=palliative care nurse practitioner; PCP= primary care provider; RN=registered nurse; SD=standard deviation; SW=social worker; WISDOM=Working to Improve discuSsions About DefibrillatOr Management.

Table D-9. Qualitative Studies: How have palliative care intervention components for patients with serious life-threatening chronic illness or conditions in ambulatory settings been implemented?

Author, Year	Arm #	Arm Name	Intervention Component	Model Type	Intervention	Administration	Intervention Components	Length of Intervention Frequency/Duration	Who Delivered Specialty
Bekelman, 2014[24]	Arm 1	Psychospiritual Intervention	NA	NA	NA	NA	NA	NA	NA
Bekelman, 2014[24]	Arm 2	Collaborative Care to Alleviate Symptoms and Adjust to Illness (CASA) intervention	NA	NA	NA	NA	NA	NA	NA
Bekelman, 2016[25]	All	NA	NA	NA	NA	NA	NA	NA	NA
Dillon, 2017[26]	All	NA	NA	NA	NA	NA	NA	NA	NA
Goff, 2019[27]	Arm 1	Usual Care	NA	NA	NA	NA	NA	NA	NA
Goff, 2019[27]	Arm 2	Shared Decision Making and Renal Supportive Care (SDM-RSC)	Triggers Shared decision making tools Multicomponent	Triggers: coaching Shared decision making tools: collaborative care Multicomponent: integrating social workers into practice	Trigger: Use of validated prognostic tool to identify patients with estimated 6 months left to live Shared decision-making tools: Communication intervention in which nephrologists and social workers communicated prognosis and advance care planning in face-to-face initial meetings with the patient, caregiver, and social worker, followed by monthly social work encounters for 18 months. Multicomponent: Communication intervention in which nephrologists and social workers communicate prognosis and provide advance care planning in face-to-face encounters with patients and families using a social work-centered algorithm. The intervention consists of an initial meeting with the patient, caregiver, social worker, and surrogate followed by monthly social work encounters for 18 months.	In person	Goals of care discussion / ACP	18 months Frequency: 1x per month Duration: NA	Social Work, MD Non-palliative care

Author, Year	Arm #	Arm Name	Intervention Component	Model Type	Intervention	Administration	Intervention Components	Length of Intervention Frequency/Duration	Who Delivered Specialty
Hobler, 2018[28]	All	NA	NA	NA	NA	NA	NA	NA	NA
Lakin, 2019[29]	Arm 1		NA	NA	NA	NA	NA	NA	NA
Lakin, 2019[29]	Arm 2	Serious Illness Care Program	Training/education: clinician Triggers Shared decision making tools	NA	NA	NA	NA	NA	NA
Long, 2014[38]	Arm 1	NA	NA	NA	NA	NA	NA	NA	NA
Long, 2014[38]	Arm 2	COPD Palliative Care Intervention	Pallitive care models	Palliative care approaches provided by non-palliative care specialists	An advance practice nurse (APN) provided palliative care intervention to people with COPD already receiving COPD-focused treatment. The APN evaluated and treated participants' dyspnea, anxiety, and depression using usual palliative care pharmacologic and nonpharmacologic interventions. Patient preferences guided the specific components of the intervention. The APN called participants weekly between clinic visits to monitor symptoms and tolerance of treatments. The APN informed the pulmonologist and palliative medicine coinvestigators about the study participants' cases. The purpose of these communications was to discuss the participants' treatment plans, including pharmacologic and nonpharmacologic interventions, and the participants' responses to the interventions.	In person	Multiple	3 months Frequency: 1x per month Duration: NA	NP Non-palliative care

Author, Year	Arm #	Arm Name	Intervention Component	Model Type	Intervention	Administration	Intervention Components	Length of Intervention Frequency/Duration	Who Delivered Specialty
Metzger, 2016[31]	Arm 1	Usual care (Multidisciplinary care from LVAD team)	NA	NA	NA	NA	NA	NA	NA
Metzger, 2016[31]	Arm 2	SPIRIT-HF	Shared decision-making tools	Coaching	One-hour long structured discussion facilitated by a PhD-prepared nurse trained in the original SPIRIT intervention, with patients with LVADs and their designated surrogate decisions makers. Discussion aimed to elicit understanding of their heart failure, the LVAD, prognosis, and life-sustaining treatment. Using this understanding, interventionist facilitated discussion between patient and surrogate regarding their thoughts on different end-of-life scenarios	In person	Goals-of-care discussion / ACP	1 visit Frequency: 1 time only Duration: 1 hour	PhD Prepared RN Non-palliative care
Nowels, 2016[32]	All	NA	NA	NA	NA	NA	NA	NA	NA

Author, Year	Arm #	Arm Name	Intervention Component	Model Type	Intervention	Administration	Intervention Components	Length of Intervention Frequency/Duration	Who Delivered Specialty
Paladino, 2019[33]	Arm 1	NA	NA	NA	NA	NA	NA	NA	NA
Paladino, 2019[33]	Arm 2	NA	Training/education: clinician	Train-the-trainer program	Three faculty conducted three train-the-trainer courses to equip faculty trainers at three institutions to teach serious illness communication. The two-day train-the-trainer curricula was based on best educational practices and adult learning theories, including attention to knowledge, attitudes, and skills-oriented practice with feedback.The goal was to prepare faculty trainers to deliver a predesigned, structured 2.5–3-hour clinician training on serious illness communication. The clinician training, tested in two research trials teaches clinicians to have conversations about patients' values, goals, and prognosis using a scalable tool, the Serious Illness Conversation Guide (''Guide''). The training involves interactive methods, including reflection, demonstration and debriefing, cognitive maps, and skills practice with feedback.	In person	Goals-of-care discussion / ACP	1 year NA	MD, RN, APP Palliative care

Author, Year	Arm #	Arm Name	Intervention Component	Model Type	Intervention	Administration	Intervention Components	Length of Intervention Frequency/Duration	Who Delivered Specialty
Rabow, 2003[34]	Arm 1	Usual Care	NA	NA	NA	NA	NA	NA	NA

Author, Year	Arm #	Arm Name	Intervention Component	Model Type	Intervention	Administration	Intervention Components	Length of Intervention Frequency/Duration	Who Delivered Specialty
Rabow, 2003[34]	Arm 2	Comprehensive Care Team (CCT)	Pallitive care models	Collaborative care	Included 7 main components. First, consultation with PCPs was based on patient assessments conducted by the social worker. The CCT developed recommendations offered to the patient's PCP via written letter and e-mail. Recommendations were offered in 5 domains: physical symptoms, psychological well-being, social support, spiritual well-being, and advance care planning. The CCT physicians based their suggestions on information from validated patient surveys and the social worker assessment. Second, the social worker provided case management and offered psychological support in person and by telephone. The social worker encouraged patients to address issues of advance care planning, including surrogate decision makers, prognosis, funeral arrangements, and wills. Third, a nurse provided family caregiver training and support through formal classes and informal individual consultation. Fourth, a pharmacist performed a medical chart review of patient medications, looking in particular for drug-drug interactions and unnecessarily complex medication regimens. Fifth, a chaplain offered each patient spiritual and psychological support. Sixth, patients and their families were invited to monthly support groups that included discussions about symptom management and advance care planning, as well as art projects called "art experientials" designed to explore emotions relating to illness and relationships. Seventh, medical and pharmacy students provided volunteer patient support and advocacy through weekly telephone contacts with patients, monthly visits, and regular communication with the CCT about patient needs	In person	Multiple	1 year NA	Multiple Palliative care

Author, Year	Arm #	Arm Name	Intervention Component	Model Type	Intervention	Administration	Intervention Components	Length of Intervention Frequency/Duration	Who Delivered Specialty
Scherer, 2018[35]	All	NA	NA	NA	NA	NA	NA	NA	NA
Song, 2017[36]	Arm 1	NA	NA	NA	NA	NA	NA	NA	NA
Song, 2017[36]	Arm 2	SPIRIT	Training/education: patient Shared decision-making tools	Coaching	SPIRIT intervention included two sessions delivered by a trained nurse interventionist. The interventionist assessed cognitive, emotional, and spiritual/religious aspects of patient's and surrogate's understanding of patient's illness, prognosis, and end-of-life care. The interventionist used this information to provide individualized information about effectiveness of life-sustaining treatment for people on dialysis, helping patients examine their own values about life-sustaining treatment, and facilitated a discussion between the patient and surrogate to prepare the surrogate for decision making.	In person	Goals-of-care discussion / ACP	2 visits NA	RN Non-palliative care
Uhler, 2015[37]	Arm 1	Usual Care	NA	Na	NA	Na	Na	NA	NA
Uhler, 2015[37]	Arm 2	InformedTogether	Shared decision making tools	Web-based tool	The InformedTogether decision aid is a Web-based platform which projects survival outcomes using patient age and disease severity which can be entered by a patient or clinician. After entering this information, several pages are produced including personalized survival estimates for Full Code vs DNR advanced directive status and a suggested script to discuss the topics of prognosis and planning in case of a COPD exacerbation	Online	Goals-of-care discussion / ACP	NA	NA

ACP= American College of Physicians; APP= American Physician Partners; CASA= Collaborative Care to Alleviate Symptoms and Adjust to Illness; CCT= Comprehensive Care Team; COPD=chronic obstructive pulmonary disease; LVAD= left ventricular assist device; MD=Doctor of Medicine; NA=not available; NP=nurse practitioner; PCP=palliative care physician; RN=registered nurse; SDM-RSC= Shared Decision Making and Renal Supportive Care; SPIRIT = Sharing Patient's Illness Representation to Increase Trust.

Table D-10. Anxiety symptom continuous outcomes for studies comparing effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Curtis, 2018[2]	Arm 1	Usual care	2 indicator latent variable	Generalized Anxiety Disorder survey (GAD-7)	288	NR	6 months	NR	Mean 0.21 (95% CI -0.05 to 0.47)	NR	Comparator: Ref	NR
Curtis, 2018[2]	Arm 2	Jumpstart-Tips	2 indicator latent variable	Generalized Anxiety Disorder survey (GAD-7)	249	NR	6 months	NR	Mean 0.3 (95% CI 0.00 to 0.59)	NR	Comparator: Arm 1 p=0.69	Baseline level on the outcome
Curtis, 2018[2]	Arm 1	Usual care	Standard composite score	Generalized Anxiety Disorder survey (GAD-7)	288	NR	6 months	NR	Mean 3.08 (95% CI 2.44 to 3.72)	NR	Comparator: Ref	NR
Curtis, 2018[2]	Arm 2	Jumpstart-Tips	Standard composite score	Generalized Anxiety Disorder survey (GAD-7)	249	NR	6 months	NR	Mean 3.375 (95% CI 2.67 to 4.08)	NR	Comparator: Arm 1 p=0.85	NR
Doorenbos, 2016[3]	Arm 1	Usual Care	Increase in anxiety	GAD-Anxiety	39	Mean 5.94 (SD 6.13)	2 weeks	34	Mean 4.15 (SD 4.7)	NR	Comparator: Ref	NR
Doorenbos, 2016[3]	Arm 2	GoC	Increase in anxiety	GAD-Anxiety	41	Mean 3.69 (SD 5.21)	2 weeks	39	Mean 3.72 (SD 5.48)	NR	Comparator: Arm 1 p=0.09	NR

CI=confidence interval; GAD= Generalized Anxiety Disorder; GoC=goals of care; N=sample size; NR=not reported; p=p-value; Ref=reference group; SD=standard deviation.

Table D-11. Concordance between preference and care received categorical outcomes for studies comparing effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results n(%)	Followup Time	Followup N	Patients with Outcomes, n(%)	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Curtis, 2018[2]	Arm 1	Usual care	Goal concordant care in full sample	NR	288	NR	3 months	83	Patients: 47 (57)	NR	Comparator: Ref p=Ref	NR
Curtis, 2018[2]	Arm 2	Jumpstart-Tips	Goal concordant care in full sample	NR	249	NR	3 months	91	Patients: 64 (70)	NR	Comparator: Arm 1 p=0.08, RR: 1.24 (95% CI: 0.99 to 1.56)	NR
Curtis, 2018[2]	Arm 1	Usual care	Goal concordant care in patients with stable preference	NR	288	NR	3 months	57	Patients: 32 (57)	NR	Comparator: Ref p=Ref	NR
Curtis, 2018[2]	Arm 2	Jumpstart-Tips	Goal concordant care in patients with stable preference	NR	249	NR	3 months	72	Patients: 53 (73)	NR	Comparator: Arm 1 p=0.03, RR: 1.31 (95% CI: 1.0 to 1.71)	NR
Kirchhoff, 2012[4]	Arm 1	Usual care	Concordance between preference and care received	NR	153	Patients: 48 (31.37)	post death	48	Patients: 48 (100)	NR	Comparator: Arm 1 Comparison: 30, p=NR	NR
Kirchhoff, 2012[4]	Arm 2	Intervention	Concordance between preference and care received	NR	160	Patients: 62 (38.75)	post death	62	Patients: 62 (100)	NR	Comparator: Arm 2 Comparison: 46, p=NR	NR

CI=confidence interval; N=sample size; NR=not reported; p=p-value; Ref=reference group; RR=relative risk.

Table D-12. Depression continuous outcomes for studies comparing effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Curtis, 2018[2]	Arm 1	Usual care	Two indicator latent variable	8-item Patient Health Questionnaire	288	NR	6 months	NR	Mean 0.24 (95% CI 0.07 to 0.42)	NR	Comparator: Ref	NR
Curtis, 2018[2]	Arm 2	Jumpstart-Tips	Two indicator latent variable	8-item Patient Health Questionnaire	249	NR	6 months	NR	Mean 0.4 (95% CI 0.11 to 0.69)	NR	Comparator: Arm 1 p=0.11	Baseline level on the outcome, age, racial/ethnic minority status, education, self identified health status, clinician type and specialty
Curtis, 2018[2]	Arm 1	Usual care	Standard composite score	8-item Patient Health Questionnaire	288	NR	6 months	NR	Mean 4.84 (95% CI 4.17 to 5.51)	NR	Comparator: Ref	NR
Curtis, 2018[2]	Arm 2	Jumpstart-Tips	Standard composite score	8-item Patient Health Questionnaire	249	NR	6 months	NR	Mean 5.927 (95% CI 5.05 to 6.81)	NR	Comparator: Arm 1 p=0.34	NR
Doorenbos, 2016[3]	Arm 1	Usual Care	Increase in depression	PHQ-9	39	Mean 7.32 (SD 6.62)	2 weeks	34	Mean 5.6 (SD 5.8)	NR	Comparator: Ref	NR
Doorenbos, 2016[3]	Arm 2	GoC	Increase in depression	PHQ-9	41	Mean 5.41 (SD 5.17)	2 weeks	39	Mean 5.47 (SD 5.03)	NR	Comparator: Arm 1 p=0.52	NR

CI=confidence interval; GoC=goals of care; N=sample size; NR=not reported; p=p-value; PHQ-9=Patient Health Questionnaire-9; Ref=reference group; SD=standard deviation.

Table D-13. Health-related quality of life continuous outcomes for studies comparing effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Au, 2012[1]	Arm 1	Control	Quality of Communication (QOL)	Previously validated quality of end-of-life communication score (QOC) was our primary outcome measure. The QOC ranges between 0 and 100, with higher scores indicating better communication.	182	Mean 19.2 (95% CI 15.9 to 22.4)	2 weeks post intervention visit	182	NA 34.0 (28.5-39.4) (NA 6.3)	Mean change from baseline: Pre 19.2 (95% CI: 15.9-22.4); Post 25.5 (95% CI: 20.4-30.5) (SD NA), p=NR	Comparator: Arm 2 QOC scale: 6.3 pointsp=0.03	Missing Data, Lost to follow up
Au, 2012[1]	Arm 2	Intervention	Quality of Communication (QOL)	Previously validated quality of end-of-life communication score (QOC) was our primary outcome measure. The QOC ranges between 0 and 100, with higher scores indicating better communication.	194	Mean 23.3 (95% CI 19.9 to 26.8)	2 weeks post intervention visit	194	NA 25.5 (20.4-30.5) (NA 10.7)	Mean change from baseline: Pre 23.3 (95% CI: 19.9-26.8); Post 34.0 (95% CI: 28.5-39.4) (SD NA), p=Post visit p=0.03	Comparator: Arm 1 QOC scale: 10.7 pointsp=0.03	Missing Data, Lost to follow up

CI=confidence interval; N=sample size; NR=not reported; p=p-value; Ref=reference group.

Table D-14. Patient satisfaction continuous outcomes for studies comparing effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Doorenbos, 2016[3]	Arm 1	Usual Care	Quality of EOL communication with provider	QOC questionnaire	39	Mean 3.9 (SD 2.82)	2 weeks	34	Mean 4.47 (SD 2.78)	NR	Comparator: Ref	NR
Doorenbos, 2016[3]	Arm 2	GoC	Quality of EOL communication with provider	QOC questionnaire	41	Mean 3.74 (SD 3.22)	2 weeks	39	Mean 5.76 (SD 3.18)	NR	Comparator: Arm 1 p=0.03	NR
Song, 2009[6]	Arm 1	Usual Care	Quality of Patient-Clinician Communication about End-of-Life Care	Quality of Patient-Clinician Communication about End-of-Life Care	29	NA	T3	29	NA	NA	Comparator: Arm 2 Difference in mean: p= 0.03	NR
Song, 2009[6]	Arm 2	Spirit	Quality of Patient-Clinician Communication about End-of-Life Care	Quality of Patient-Clinician Communication about End-of-Life Care	29	NA	T3	27	NA	NA	Comparator: Ref Difference in mean: U = 165.00, p< .01	NR

EOL=end of life; GoC=goals of care; N=sample size; NA=not available; NR=not reported; p=p-value; QOC=quality of communication; SD=standard deviation; T=timepoint; U=Mann–Whitney U test.

Table D-15. Caregiver satisfaction continuous outcomes for studies comparing effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Song, 2009[6]	Arm 1	Usual Care	Quality of Patient-Clinician Communication about End -of-Life Care	Quality of Patient-Clinician Communication about End-of-Life Care	29	NR	T3	27	NR	NR	Comparator: Arm 2 Difference in mean: 10.22 (SD 2.49), p=NR	NR
Song, 2009[6]	Arm 2	SPIRIT	Quality of Patient-Clinician Communication about End-of-Life Care	Quality of Patient-Clinician Communication about End-of-Life Care	29	NR	T3	27	NR	NR	Comparator: Ref Difference in mean: 11.58 (SD 0.72), p=NR	NR

N=sample size; NR=not reported; p=p-value; Ref=reference group; SD=standard deviation; T=timepoint.

Table D-16. Advance directive documentation categorical outcomes for studies comparing effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Patients with Outcomes, n(%)	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Curtis, 2018[2]	Arm 1	Usual care	All patient-EHR Documentation of Goals-of-Care Discussion at Clinic Visit, %	NR	288	NR	3 months	NR	Patients: NR (17)	NR	Comparator: Ref p=Ref	NR
Curtis, 2018[2]	Arm 2	Jumpstart-Tips	All patient-EHR Documentation of Goals-of-Care Discussion at Clinic Visit, %	NR	249	NR	3 months	NR	Patients: NR (62)	NR	Comparator: Arm 1 p< 0.001	NR
Curtis, 2018[2]	Arm 1	Usual care	Patients who did not object to discussion-EHR Documentation of Goals-of-Care Discussion at Clinic Visit, %	NR	288	NR	3 months	NR	Patients: NR (17)	NR	Comparator: Ref p=Ref	NR
Curtis, 2018[2]	Arm 2	Jumpstart-Tips	Patients who did not object to discussion-EHR Documentation of Goals-of-Care Discussion at Clinic Visit, %	NR	249	NR	3 months	NR	Patients: NR (63)	NR	Comparator: Arm 1 p< 0.001	NR
Doorenbos, 2016[3]	Arm 1	Usual Care	Advance directive	NR	39	NR	After-visit outcomes (~2 weeks)	NR	Patients: 3 (7.7)	NR	Comparator: Ref	NR
Doorenbos, 2016[3]	Arm 2	GoC	Advance directive	NR	41	NR	After-visit outcomes (~2 weeks)	NR	Patients: 7 (16.1)	NR	Comparator: Arm 1 p=0.24	NR

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Patients with Outcomes, n(%)	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Perry, 2005[5]	Arm 1	Control	Advance directive documentation	NR	81	Patients: 8 (10)	4 months	81	Patients: 8 (10)	NR	Comparator: Arm 3 OR: 0.2, p=0.01 RR: 0.28 (95% CI: 0.14 to 0.59)	NR
Perry, 2005[5]	Arm 2	Printed	Advance directive documentation	NR	59	Patients: 7 (12)	4 months	59	Patients: 7 (12)	NR	Comparator: Arm 3 OR: 0.25, p=0.01 RR: 0.34 (95% CI: 0.16 to 0.74)	NR
Perry, 2005[5]	Arm 3	Peer intervention	Advance directive documentation	NR	63	Patients: 22 (35)	4 months	63	Patients: 22 (35)	NR	Comparator: Ref p=Ref	NR

CI=confidence interval; EHR=electronic health record; GoC=goals of care; N=sample size; NR=not reported; OR=odds ratio; p=p-value; Ref=reference group; RR=relative risk.

Table D-17. Dropout categorical outcomes for studies comparing effectiveness of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Patients with Outcomes, n(%)	Notes
Au, 2012[1]	Arm 1	Control	Dropouts	NR	182	NR	NR	NR	NR	Dropouts due to intervention is not reported, unable to discern from article.
Au, 2012[1]	Arm 2	Intervention	Dropouts	NR	194	NR	NR	NR	NR	Dropouts due to intervention is not reported, unable to discern from article.

N=sample size; NR=not reported.

Table D-18. Anxiety symptoms continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Bekelman, 2018[8]	Arm 1	Usual care	Anxiety symptom	7-item Generalized Anxiety Disorder Questionnaire	108	NR	3 month	108	NR	Mean change from baseline: -0.3 (SD NR), p=NR	Comparator: Ref p=Ref	NR
Bekelman, 2018[8]	Arm 2	CASA	Anxiety symptom	7-item Generalized Anxiety Disorder Questionnaire	110	NR	3 month	110	NR	Mean change from baseline: -1.4 (SD NR), p=NR	Comparator: Arm 1 Difference in mean: -0.9 (95% CI: −2.06 to −0.11), p<0.001	NR
Kluger, 2020[14]	Arm 1	Standard Care	Anxiety symptom	Hospital Anxiety and Depression Scale	102	Mean 7.73 (4.43)	12 months	85	Mean 5.94 (3.76)	Mean change from baseline: -1.42 (95% CI: -2.04 to -0.8), p<0.001	Comparator: Ref	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn andY ahr stage, study site, and presence of a caregiver, race, marital status, education level

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Kluger, 2020[14]	Arm 2	Palliative Care Intervention	Anxiety symptom	Hospital Anxiety and Depression Scale	105	Mean 7.57 (3.78)	12 months	87	Mean 6.01 (4.03)	Mean change from baseline: -1.3 (95% CI: 1.91 to -0.69), p<0.001	Comparator: Arm 1 Difference in mean: 0.12 (95% CI: -0.71 to 0.95), p=0.78 SMD: 0.03 (95% CI: -0.27 to 0.33)	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level
Feely, 2016[12]	Overall	All	Anxiety symptoms	Modified Edmonton Symptom Assessment Scale (MESAS)	53	Mean 0.98 (SD 1.82)	2 weeks after pilot completion	53	Mean 1.08 (SD 2.86)	p=0.8	Comparator: NA	NR

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
O'Donnell, 2018[18]	Arm 1	Control	Change from baseline in anxiety among 6 months survivors	GAD-7	24	Mean 6.2 (SD 5.4)	6 months	15	Mean 4.7 (SD 5.5)	Mean change from baseline: -2.6 (SD 4.8), p=NR	Comparator: Arm 2 p=Ref	Baseline
O'Donnell, 2018[18]	Arm 2	Intervention	Change from baseline in anxiety among 6 months survivors	GAD-7	26	Mean 5.7 (SD 5.6)	6 months	16	Mean 2.9 (SD 3.3)	Mean change from baseline: -3 (SD 4.5), p=NR	Comparator: Arm 1 Difference in mean: p=0.38 SMD: -0.09 (95% CI: -0.79 to 0.62)	Baseline
O'Riordan, 2019[19]	Arm 1	Usual Care	Anxiety symptom	HADS	14	Mean 7.4 (95% CI: 4.9 to 9.9)	6 months	14	Mean 4.9 (95% CI: 2.2 to 7.5)	p=NR	Comparator: Ref	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
O'Riordan, 2019[19] (continued)	Arm 2	PC Intervention	Anxiety symptom	HADS	16	Mean 5.9 (95% CI: 3.5 to 8.2)	6 months	16	Mean 5.4 (95% CI: 3.0 to 7.9)	p=0.003	Comparator: Arm 1 p=NS	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject
Owens, 2012[20]	Overall	Overall	Anxiety symptoms	ESAS	34	Mean 1.65 (SD 2.47)	Average of all assessments	NR	Mean 1.94 (SD 2.5)	NR	Comparator: NR	NR
Owens, 2012[20]	Arm 2	Not Cancer	Anxiety symptoms	ESAS	14	Mean 2 (SD 2.63)	Average of all assessments	NR	Mean 2.6 (SD 3.06)	NR	Comparator: NR	NR
Rabow, 2004[21, 22]	Arm 1	Control	Anxiety symptoms	Profile of Mood States	40	Mean 6.1 (SD NR)	1 year	40	Mean 5.9 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Anxiety symptoms	Profile of Mood States	50	Mean 7.4 (SD NR)	1 year	50	Mean 5.3 (SD NR)	NR	Comparator: Control p=0.68	Baseline values
Rogers, 2017[23]	Arm 1	UC Alone	Anxiety symptoms	HADS-anxiety	75	NR	6 months	38	Mean 6.2 (SD 4.8)	NR	Comparator: intervention Difference in mean: p=Ref	Age, sex
Rogers, 2017[23]	Arm 2	UC + PAL	Anxiety symptoms	HADS-anxiety	75	NR	6 months	41	Mean 3.7 (SD 4)	NR	Comparator: Arm 1 Difference in mean: -1.7 (95% CI: -3.5 to 0.09), p=0.063	NR

CASA=Collaborative Care to Alleviate Symptoms and Adjust to Illness; CI=confidence interval; ESAS=Edmonton Symptom Assessment Scale; GAD-7=General Anxiety Disorder-7; HADS=Hospital Anxiety and Depression Scale; N=sample size; NA=not available; NR=not reported; p=p-value; PAL= palliative care intervention; Ref=reference group; SD=standard deviation; UC=usual care.

Table D-19. Depression symptoms continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Bekelman, 2018[8]	Arm 1	Usual care	Depression symptom	9-item Patient Health Questionnaire	105	NR	3 month	105	NR	Mean change from baseline: -0.5 (SD NR), p=NR	Comparator: Ref Difference in mean: p=Ref	NR
Bekelman, 2018[8]	Arm 2	CASA	Depression symptom	9-item Patient Health Questionnaire	105	NR	3 month	105	NR	Mean change from baseline: -2.1 (SD NR), p=NR	Comparator: Arm 1 Difference in mean: -1.6 (95% CI: −2.7 to −0.4), p=0.01	NR
Bekelman, 2015[7]	Arm 1	Usual care	PHQ9 score	PHQ9	77	NR	1 year	NR	NR	NR	Comparator: Ref	NR
Bekelman, 2015[7]	Arm 2	Intervention	PHQ9 score	PHQ9	78	NR	1 year	NR	NR	NR	Comparator: Arm 1 Not reported: 2.1 (95% CI: 0.43 to 3.78), p=0.01	NR
Feely, 2016[12]	Overall	All	Depression symptoms	Modified Edmonton Symptom Assessment Scale (MESAS)	53	Mean 0.96 (SD 1.99)	2 weeks after pilot completion	53	Mean 0.87 (SD 2.29)	p=0.7	Comparator: NA	NR

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Kluger, 2020[14]	Arm 1	Standard Care	Depression symptoms	Hospital Anxiety and Depression Scale	102	Mean 7.23 (3.74)	12 months	85	Mean 6.91 (3.94)	Mean change from baseline: 0.12 (95% CI: -0.45 to 0.69), p=0.66	Comparator: Ref	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Kluger, 2020[14] (continued)	Arm 2	Palliative Care Intervention	Depression symptoms	Hospital Anxiety and Depression Scale	105	Mean 7.04 (3.55)	12 months	87	Mean 6.44 (3.83)	Mean change from baseline: -0.33 (95% CI: -0.92 to 0.25), p=0.26	Comparator: Arm 1 Difference in mean: -0.52 (95% CI: -1.33 to 0.29), p=0.21 SMD: -0.09 (95% CI: -0.39 to 0.21)	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level
O'Donnell, 2018[18]	Arm 1	Control	Change from baseline in depression among 6 months survivors	PHQ-8	24	Mean 8.9 (SD 5.3)	6 months	15	Mean 8.1 (SD 7.2)	Mean change from baseline: -0.8 (SD 4.3), p=NR	Comparator: Arm 2 p=Ref	Baseline
O'Donnell, 2018[18]	Arm 2	Intervention	Change from baseline in depression among 6 months survivors	PHQ-8	25	Mean 7.9 (SD 4.7)	6 months	16	Mean 5.9 (SD 4.4)	Mean change from baseline: -1.4 (SD 3.8), p=NR	Comparator: Arm 1 Difference in mean: p=0.52	Baseline

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
O'Donnell, 2018[18]	Arm 1	Control	Change from baseline in depression among 6 months survivors	PHQ-8	24	Mean 8.9 (SD 5.3)	6 months	15	Mean 8.1 (SD 7.2)	Mean change from baseline: -0.8 (SD 4.3), p=NR	Comparator: Arm 2 p=Ref	Baseline
O'Donnell, 2018[18]	Arm 2	Intervention	Change from baseline in depression among 6 months survivors	PHQ-8	25	Mean 7.9 (SD 4.7)	6 months	16	Mean 5.9 (SD 4.4)	Mean change from baseline: -1.4 (SD 3.8), p=NR	Comparator: Arm 1 Difference in mean: p=0.52	Baseline
O'Riordan, 2019[19]	Arm 1	Usual Care	Depression symptoms	HADS	14	Mean 6.5 (95% CI: 4.4 to 8.6)	6 months	14	Mean 5.9 (95% CI: 3.6 to 8.1)	p=NR	Comparator: Ref	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
O'Riordan, 2019[19] (continued)	Arm 2	PC Intervention	Depression symptoms	HADS	16	Mean 5.4 (95% CI: 3.4 to 7.4)	6 months	16	Mean 4.7 (95% CI: 2.6 to 6.8)	Arm 1: p=0.15	Comparator: Arm 1 p=NS SMD: -0.02 (95% CI: -0.74 to 0.69)	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject
Owens, 2012[20]	Overall	Overall	Depression symptoms	ESAS or BPAS (if cognitively impaired)	33	Mean 2.64 (SD 3.19)	Average of all assessments	NR	Mean 2.7 (SD 2.74)	NR	Comparator: NR	NR
Owens, 2012[20]	Arm 2	Not Cancer	Depression symptoms	ESAS or BPAS (if cognitively impaired)	13	Mean 2.92 (SD 3.15)	Average of all assessments	NR	Mean 3.33 (SD 2.85)	NR	Comparator: NR	NR
Rabow, 2004[21, 22]	Arm 1	Control	Depression symptoms	Center for Epidemiological Studies Depression Scale	40	Mean 16.8 (SD NR)	1 year	40	Mean 15.3 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Depression symptoms	Center for Epidemiological Studies Depression Scale	50	Mean 19.1 (SD NR)	1 year	50	Mean 12.4 (SD NR)	NR	Comparator: Control p=0.28	Baseline values

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Rogers, 2017[23]	Arm 1	UC Alone	Depression symptoms	HADS-depression	75	NR	6 months	39	Mean 6.4 (SD 4.3)	NR	Comparator: intervention Difference in mean: p=Ref	Age, sex
Rogers, 2017[23]	Arm 2	UC + PAL	Depression symptoms	HADS-depression	75	NR	6 months	41	Mean 4.6 (SD 3.6)	NR	Comparator: Arm 1 Difference in mean: -1.94 (95% CI: -3.58 to -0.3), p=0.021	Age, sex

BPAS=Behavioral Pain Assessment Score; CASA=Collaborative Care to Alleviate Symptoms and Adjust to Illness; CI=confidence interval; ESAS=Edmonton Symptom Assessment Scale; HADS=Hospital Anxiety and Depression Scale; N=sample size; NR=not reported; p=p-value; PAL= palliative care intervention; PHQ-8=8-item Patient Health Questionnaire; PHQ-9=9-item Patient Health Questionnaire-9; Ref=reference group; SD=standard deviation; UC=usual care.

Table D-20. Dyspnea continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Bekelman, 2018[8]	Arm 1	Usual care	Scores range from 0 to 10; a higher number means more shortness of breath	NR	113	NR	3 month	113	NR	Mean change from baseline: -0.6 (SD NR), p=NR	Comparator: Ref Difference in mean: p=Ref	NR
Bekelman, 2018[8]	Arm 2	CASA	Scores range from 0 to 10; a higher number means more shortness of breath	NR	110	NR	3 month	110	NR	Mean change from baseline: -0.7 (SD NR), p=NR	Comparator: Arm 1 Difference in mean: -0.1 (95% CI: −0.7 to 0.4), p=0.67	NR
Feely, 2016[12]	Overall	All	Dyspnea	Modified Edmonton Symptom Assessment Scale (MESAS)	53	Mean 0.34 (SD 1.06)	2 weeks after pilot completion	53	Mean 1.06 (SD 1.95)	p=0.009	Comparator: NA	NR
O'Riordan, 2019[19]	Arm 1	Usual Care	Dyspnea	BORG scale	14	Mean 4.5 (95% CI: 2.7 to 6.2)	6 months	14	Mean 2.4 (95% CI: 1.1 to 3.8)	p=Ref	Comparator: Ref	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
O'Riordan, 2019[19] (continued)	Arm 2	PC Intervention	Dyspnea	BORG scale	16	Mean 3.4 (95% CI: 1.8 to 5.0)	6 months	16	Mean 1.9 (95% CI: 0.6 to 3.2)	Arm 1: p=0.03	Comparator: Arm 1 p=NS	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject
Owens, 2012[20]	Overal l	Overall	Dyspnea	ESAS	35	Mean 1.57 (SD 2.63)	Average of all assessme nts	NR	Mean 1.75 (SD 2.24)	NR	Comparator: NR	NR
Owens, 2012[20]	Arm 2	Not Cancer	Dyspnea	ESAS	14	Mean 2 (SD 3.21)	Average of all assessme nts	NR	Mean 2.09 (SD 2.51)	NR	Comparator: NR	NR

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Rabow, 2004[21, 22]	Arm 1	Control	Dyspnea interferes score	University of California, San Diego Shortness of Breath Questionnaire	40	Mean 36.1 (SD NR)	1 year	40	Mean 40.6 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Dyspnea interferes score	University of California, San Diego Shortness of Breath Questionnaire	50	Mean 44.8 (SD NR)	1 year	50	Mean 25.4 (SD NR)	NR	Comparator: Control p=0.01	Baseline values
Rabow, 2004[21, 22]	Arm 1	Control	Dyspnea limits score	University of California, San Diego Shortness of Breath Questionnaire	40	Mean 36.1 (SD NR)	1 year	40	Mean 7.1 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Dyspnea limits score	University of California, San Diego Shortness of Breath Questionnaire	50	Mean 44.5 (SD NR)	1 year	50	Mean 3.6 (SD NR)	NR	Comparator: Control p=0.07	Baseline values

CASA=Collaborative Care to Alleviate Symptoms and Adjust to Illness; CI=confidence interval; ESAS=Edmonton Symptom Assessment Scale; N=sample size; NR=not reported; p=p-value; PAL= palliative care intervention; Ref=reference group; SD=standard deviation; UC=usual care.

Table D-21. Fatigue continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Bekelman, 2018[8]	Arm 1	Usual care	The Patient-Reported Outcomes Measurement Information System Short Form 8a measured fatigue (range, 0-48; higher score indicates more fatigue).	PROMIS	107	NR	3 month	107	NR	Mean change from baseline: -1.1 (SD NR), p=NR	Comparator: Ref	NR
Bekelman, 2018[8]	Arm 2	CASA	The Patient-Reported Outcomes Measurement Information System Short Form 8a measured fatigue (range, 0-48; higher score indicates more fatigue).	PROMIS	107	NR	3 month	107	NR	Mean change from baseline: -2.3 (SD NR), p=NR	Comparator: Arm 1 Difference in mean: -1.2 (95% CI: −2.7 to 0.4), p=0.14	NR
Feely, 2016[12]	Overall	All	Fatigue	Modified Edmonton Symptom Assessment Scale (MESAS)	53	Mean 2.98 (SD 3.22)	2 weeks after pilot completion	53	Mean 4.06 (SD 2.69)	p=0.02	Comparator: NA	NR
Owens, 2012[20]	Overall	Overall	Fatigue	ESAS	35	Mean 5.49 (SD 3.16)	Average of all assessments	NR	Mean 4.98 (SD 2.52)	NR	Comparator: NR	NR
Owens, 2012[20]	Arm 2	Not Cancer	Fatigue	ESAS	14	Mean 5.64 (SD 2.76)	Average of all assessments	NR	Mean 4.99 (SD 2.19)	NR	Comparator: NR	NR

CASA=Collaborative Care to Alleviate Symptoms and Adjust to Illness; CI=confidence interval; ESAS=Edmonton Symptom Assessment Scale; N=sample size; NR=not reported; p=p-value; PROMIS= Patient-Reported Outcomes Measurement Information System; Ref=reference group; SD=standard deviation.

Table D-22. Health-related quality of life continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Bekelman, 2018[8]	Arm 1	Usual care	Overall symptom distress	General Symptom Distress Scale (GSDS)	157	NR	6 months	122	NR	Mean change from baseline: -0.5 (SD NR), p=NR	Comparator: Ref	NR
Bekelman, 2018[8]	Arm 2	CASA	Overall symptom distress	General Symptom Distress Scale (GSDS)	157	NR	6 months	124	NR	Mean change from baseline: -0.4 (SD NR), p=NR	Comparator: Arm 1 Difference in mean: 0.1 (95% CI: (-0.5 to 0.7)), p=0.8	NR
Bekelman, 2018[8]	Arm 1	Usual care	Health-related quality of life	KCCQ	157	Mean 45.3 (SD 21)	6 months	121	NR	Mean change from baseline: 2.9 (SD NR), p=NR	Comparator: Ref Difference in mean: p=Ref	NR
Bekelman, 2018[8]	Arm 2	CASA	Health-related quality of life	KCCQ	157	Mean 48.6 (SD 17.4)	6 months	121	NR	Mean change from baseline: 5.5 (SD NR), p=NR	Comparator: Arm 1 Difference in mean: 2.6 (95% CI: -1.3 to 6.6), p=0.19	NR
Bekelman, 2015[7]	Arm 1	Usual care	Health-related quality of life	KCCQ	197	Mean 36.9 (SD 14.6)	1 year	NR	NR	Mean change from baseline: 13.5 (SD NR), p=Ref	Comparator: Ref	NR
Bekelman, 2015[7]	Arm 2	Intervention	Health-related quality of life	KCCQ	187	Mean 37.9 (SD 13.3)	1 year	NR	NR	Mean change from baseline: 13.5 (SD NR), p=0.97	Comparator: Arm 1 NR	NR
Bekelman, 2015[7]	Arm 1	Usual care	Model estimated summary score	KCCQ	197	Mean 36.9 (SD 14.6)	1 year	NR	Mean 53.6 (95% CI: 51.1 to 56)	NR	Comparator: NR	NR
Bekelman, 2015[7]	Arm 2	Intervention	Model estimated summary score	KCCQ	187	Mean 37.9 (SD 13.3)	1 year	NR	Mean 54.2 (95% CI: 51.7 to 56.6)	NR	Comparator: NR	NR

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Engelhardt, 2009[11]	Arm 1	Usual Care	Health-related quality of life	McGill Quality of Life Questionnaire	NR	Mean 4.77 (SD 0.97)	NR	NR	Mean 4.89 (SD 1.14)	NR	Comparator: Ref p=Ref	Baseline scores, age and sex
Engelhardt, 2009[11]	Arm 2	AICCP	Health-related quality of life	McGill Quality of Life Questionnaire	NR	Mean 4.9 (SD 0.89)	NR	NR	Mean 5.03 (SD 0.87)	NR	Comparator: Arm 1 Difference in mean: p=NS	Baseline scores, age and sex
Kluger, 2020[14]	Arm 1	Standard Care	Health-related quality of life	Quality of Life in Alzheimer's Disease	101	Mean 34.3 (5.6)	12 months	84	Mean 34.37 (6.38)	Mean change from baseline: -0.43 (95% CI: -1.37 to 0.5), p=0.36	Comparator: Ref	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Kluger, 2020[14] (continued)	Arm 2	Palliative Care Intervention	Health-related quality of life	Quality of Life in Alzheimer's Disease	104	Mean 33.9 (5.7)	12 months	92	Mean 34.69 (6.33)	Mean change from baseline: 0.68 (95% CI: -0.38 to 0.73), p=0.21	Comparator: Arm 1 Difference in mean: 1.36 (95% CI: -0.01 to 2.73), p=0.05 SMD: 0.31 (95% CI: 0.01 to 0.61)	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level
O'Donnell, 2018[18]	Arm 1	Control	Change from baseline in HR QOL among 6 months survivors	KCCQ-12	22	Mean 37.5 (SD 20)	6 months	15	Mean 52.8 (SD 27.3)	Mean change from baseline: 13.9 (SD 27.6), p=NR	Comparator: Arm 2 p=Ref	Baseline
O'Donnell, 2018[18]	Arm 2	Intervention	Change from baseline in HR QOL among 6 months survivors	KCCQ-12	25	Mean 40.1 (SD 22.2)	6 months	16	Mean 50.2 (SD 21.5)	Mean change from baseline: 11.5 (SD 20.6), p=NR	Comparator: Arm 1 Difference in mean: p=0.95 SMD: -0.10 (95% CI: -0.80 to 0.61)	Baseline

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
O'Riordan, 2019[19]	Arm 1	Usual Care	Health-related quality of life	MLHFQ	14	Mean 60 (95% CI: 46.8 to 73.2)	6 months	14	Mean 45.4 (95% CI: 31.3 to 59.4)	p=Ref	Comparator: Ref	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject
O'Riordan, 2019[19]	Arm 2	PC Intervention	Health-related quality of life	MLHFQ	16	Mean 58.4 (95% CI: 46.1 to 70.8)	6 months	16	Mean 40 (95% CI: 27.1 to 52.8)	Arm 1: p=0.001	Comparator: Arm 1 p=NS SMD: -0.15 (95% CI: -0.87 to 0.57)	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
O'Riordan, 2019[19]	Arm 1	Usual Care	Health-related quality of life	FACIT-PAL	14	Mean 115 (95% CI: 102 to 128)	6 months	14	Mean 126 (95% CI: 113 to 143)	p=Ref	Comparator: Ref	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject
O'Riordan, 2019[19]	Arm 2	PC Intervention	Health-related quality of life	FACIT-PAL	16	Mean 122 (95% CI: 110 to 134)	6 months	16	Mean 128 (95% CI: 112 to 140)	Arm 1: p=0.03	Comparator: Arm 1 p=NS SMD: -0.19 (95% CI: --0.91 to -53)	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Rabow, 2004[21, 22]	Arm 1	Control	Single item (0 - 10)	Multidimensional Quality of Life Scale - Cancer Version	40	Mean 7.4 (SD NR)	1 year	40	Mean 7.1 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Single item (0 - 10)	Multidimensional Quality of Life Scale - Cancer Version	50	Mean 6.9 (SD NR)	1 year	50	Mean 7.5 (SD NR)	NR	Comparator: Control p=0.34	Baseline values
Rabow, 2004[21, 22]	Arm 1	Control	Total scale score (0 - 100)	Multidimensional Quality of Life Scale - Cancer Version	40	Mean 67.7 (SD NR)	1 year	40	Mean 67.7 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Total scale score (0 - 100)	Multidimensional Quality of Life Scale - Cancer Version	50	Mean 63.2 (SD NR)	1 year	50	Mean 69.3 (SD NR)	NR	Comparator: Control p=0.43	Baseline values

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Rogers, 2017[23]	Arm 1	UC Alone	Health-related quality of life	Kansas City cardiomyopathy questionnaire (KCCQ)	74	Mean 31.4 (SD 16.4)	6 months	40	Mean 52.1 (SD 25)	Mean change from baseline: 22.2 (SD 24.69), p=NR	Comparator: intervention Difference in mean: p=Ref	Age, sex
Rogers, 2017[23]	Arm 2	UC + PAL	Health-related quality of life	Kansas City cardiomyopathy questionnaire (KCCQ)	73	Mean 36.1 (SD 19.8)	6 months	41	Mean 63.1 (SD 20.4)	Mean change from baseline: 26.3 (SD 19.42), p=NR	Comparator: Arm 1 Difference in mean at 6 months only: 9.14 (95% CI: 0.56 to 17.72), p=0.037 SMD: 0.18 (95% CI: -0.25 to 0.62)	Age, sex
Rogers, 2017[23]	Arm 1	UC Alone	Health-related quality of life	Functional assessment of chronic illness therapy PC scale (FACIT-PAL)	74	Mean 118 (SD 25.1)	6 months	40	Mean 125.8 (SD 30.7)	Mean change from baseline: 8.3 (SD 29.1), p=NR	Comparator: intervention Difference in mean: p=Ref	Age, sex
Rogers, 2017[23]	Arm 2	UC + PAL	Health-related quality of life	Functional assessment of chronic illness therapy PC scale (FACIT-PAL)	74	Mean 120.6 (SD 27)	6 months	41	Mean 136.5 (SD 28.6)	Mean change from baseline: 16.7 (SD 21.1), p=NR	Comparator: Arm 1 Difference in mean at 6 months only: 11.09 (95% CI: 0.19 to 21.99), p=0.0462 SMD: 0.33 (95% CI: -0.11 to 0.77)	Age, sex

CASA=Collaborative Care to Alleviate Symptoms and Adjust to Illness; CI=confidence interval; ESAS=Edmonton Symptom Assessment Scale; FACIT-PAL= Functional assessment of chronic illness therapy palliative care scale; KCCQ= Kansas City cardiomyopathy questionnaire; N=sample size; NR=not reported; p=p-value; PAL= palliative care intervention; PROMIS= Patient-Reported Outcomes Measurement Information System; Ref=reference group; SD=standard deviation; SMD=standardized mean difference; UC=usual care.

Table D-23. Pain continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Bekelman, 2018[8]	Arm 1	Usual care	The PEG (3 items, derived from the Brief Pain Inventory) measured pain intensity (P), interference with enjoyment of life (E), and interference with general activity (G) (range, 0-30; higher score indicates more pain	PEG	107	NR	3 month	107	NR	Mean change from baseline: -0.8 (SD NR), p=NR	Comparator: Ref Difference in mean: p=Ref	NR
Bekelman, 2018[8]	Arm 2	CASA	The PEG (3 items, derived from the Brief Pain Inventory) measured pain intensity (P), interference with enjoyment of life (E), and interference with general activity (G) (range, 0-30; higher score indicates more pain	PEG	110	NR	3 month	110	NR	Mean change from baseline: -0.5 (SD NR), p=NR	Comparator: Arm 1 Difference in mean: 0.3 (95% CI: −0.3 to 0.9), p=0.3	NR
Feely, 2016[12]	Overall	All	Pain	Modified Edmonton Symptom Assessment Scale (MESAS)	53	Mean 1.34 (SD 2.39)	2 weeks after pilot completion	53	Mean 2.04 (SD 2.47)	p=0.04	Comparator: NA	NR

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
O'Riordan, 2019[19]	Arm 1	Usual Care	Pain	Brief Pain Inventory	14	Mean 4.1 (95% CI: 2.2 to 5.9)	6 months	14	Mean 2.2 (95% CI: 0.2 to 4.1)	p=Ref	Comparator:	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject
O'Riordan, 2019[19]	Arm 2	PC Intervention	Pain	Brief Pain Inventory	16	Mean 4.6 (95% CI: 2.5 to 6.6)	6 months	16	Mean 2.5 (95% CI: 0.4 to 4.5)	Arm 1: p=0.05	Comparator: Arm 1 p=NS	Mixed effect model adjusted for sources of variation and correlation among repeated measures within a subject

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Owens, 2012[20]	Overall	Overall	Pain	ESAS	49	Mean 3.59 (SD 3.11)	Average of all assessments	NR	Mean 3.74 (SD 2.57)	NR	Comparator: NR	NR
Owens, 2012[20]	Arm 2	Not Cancer	Pain	ESAS	28	Mean 3.04 (SD 2.9)	Average of all assessments	NR	Mean 3.55 (SD 2.59)	NR	Comparator: NR	NR
Rabow, 2004[21, 22]	Arm 1	Control	Worst	Brief Pain Inventory	40	Mean: NR	1 year	40	Mean 5.6 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Worst	Brief Pain Inventory	50	Mean: NR	1 year	50	Mean 4.8 (SD NR)	NR	Comparator: Control p=0.83	Baseline values
Rabow, 2004[21, 22]	Arm 1	Control	Least	Brief Pain Inventory	40	Mean: NR	1 year	40	Mean 2.8 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Least	Brief Pain Inventory	50	Mean: NR	1 year	50	Mean 1.8 (SD NR)	NR	Comparator: Control p=0.1	Baseline values
Rabow, 2004[21, 22]	Arm 1	Control	Average	Brief Pain Inventory	40	Mean 4.1 (SD NR)	1 year	40	Mean 4.5 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Average	Brief Pain Inventory	50	Mean 4.1 (SD NR)	1 year	50	Mean 3.6 (SD NR)	NR	Comparator: Control p=0.41	Baseline values
Rabow, 2004[21, 22]	Arm 1	Control	Right now	Brief Pain Inventory	40	Mean: NR	1 year	40	Mean 2.1 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Right now	Brief Pain Inventory	50	Mean: NR	1 year	50	Mean 2.3 (SD NR)	NR	Comparator: Control p=0.91	Baseline values
Rabow, 2004[21, 22]	Arm 1	Control	Relief (0 - 100)	Brief Pain Inventory	40	Mean: NR	1 year	40	Mean 59.8 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Relief (0 - 100)	Brief Pain Inventory	50	Mean: NR	1 year	50	Mean 68.7 (SD NR)	NR	Comparator: Control p=0.41	Baseline values

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Rabow, 2004[21, 22]	Arm 1	Control	Interferes with activities (0 - 70)	Brief Pain Inventory	40	Mean: NR	1 year	40	Mean 40.8 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Interferes with activities (0 - 70)	Brief Pain Inventory	50	Mean: NR	1 year	50	Mean 36.4 (SD NR)	NR	Comparator: Control p=0.94	Baseline values

CASA=Collaborative Care to Alleviate Symptoms and Adjust to Illness; CI=confidence interval; ESAS=Edmonton Symptom Assessment Scale; N=sample size; NA=not available; NR=not reported; p=p-value; PEG=Pain, Enjoyment, General Activity scale; Ref=reference group; SD=standard deviation.

Table D-24. Patient satisfaction continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Engelhardt, 2006[10]	Arm 1	Usual Care	Satisfaction with care	Investigator-constructed 10-item scale, 5-point, Likert-type scale	142	Mean 3.83 (SD 0.76)	NR	100	Mean 3.98 (SD 0.67)	NR	Comparator: Arm 1 p=Ref	NR
Engelhardt, 2006[10]	Arm 2	AICCP	Satisfaction with care	Investigator-constructed 10-item scale, 5-point, Likert-type scale	133	Mean 3.7 (SD 0.74)	NR	86	Mean 4.07 (SD 0.68)	NR	Comparator: Arm 2 p=0.03	NR
O'Riordan, 2019[19]	Arm 1	Usual Care	Satisfaction with care	NR	14	NR	6 months	14	NR	NR	Comparator: Ref	NR
O'Riordan, 2019[19]	Arm 2	PC Intervention	Satisfaction with care	NR	16	NR	6 months	16	NR	NR	Comparator: Arm 1 p=NS	NR
Rabow, 2004[21, 22]	Arm 1	Control	Satisfaction with care (20 - 100)	Group Health Association of America Consumer Satisfaction Survey	40	Mean 73.7 (SD NR)	1 year	40	Mean 72.4 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Satisfaction with care (20 - 100)	Group Health Association of America Consumer Satisfaction Survey	50	Mean 77 (SD NR)	1 year	50	Mean 70.1 (SD NR)	NR	Comparator: Control p=0.26	Baseline values
Rabow, 2004[21, 22]	Arm 1	Control	Attitudes toward care (4 - 20)	Group Health Association of America Consumer Satisfaction Survey	40	Mean 13.4 (SD NR)	1 year	40	Mean 13.1 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Attitudes toward care (4 - 20)	Group Health Association of America Consumer Satisfaction Survey	50	Mean 14 (SD NR)	1 year	50	Mean 12.3 (SD NR)	NR	Comparator: Control p=0.7	Baseline values

AICCP= Advanced Illness Coordinated Care Program; N=sample size; NR=not reported; p=p-value; Ref=reference group; SD=standard deviation.

Table D-25. Psychological well-being continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Engelhardt, 2009[11]	Arm 1	Usual Care	Psychological well-being	Functional Assessment of Chronic Illness - Therapy-Spiritual Well-Being Scale	NR	Mean 31.16 (SD 10.12)	NR	NR	Mean 32.05 (SD 10.53)	NR	Comparator: Ref	Baseline scores, age and sex
Engelhardt, 2009[11]	Arm 2	AICCP	Psychological well-being	Functional Assessment of Chronic Illness - Therapy-Spiritual Well-Being Scale	NR	Mean 33.28 (SD 9.65)	NR	NR	Mean 34.43 (SD 9.03)	NR	Comparator: Arm 1 p< 0.05	Baseline scores, age and sex
Kluger, 2020[14]	Arm 1	Standard Care	Psychological well-being	Functional Assessment of Chronic Illness Therapy - Spiritual Wellbeing	100	Mean 27.76 (9.75)	12 months	86	Mean 30.63 (10.08)	Mean change from baseline: 2.3 (95% CI: 0.76 to 3.83), p=0.004	Comparator: Ref	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Kluger, 2020[14]	Arm 2	Palliative Care Intervention	Psychological well-being	Functional Assessment of Chronic Illness Therapy - Spiritual Wellbeing	103	Mean 28.01 (9.58)	12 months	87	Mean 28.99 (9.59)	Mean change from baseline: 0.61 (95% CI: -0.83 to 2.04), p=0.4	Comparator: Arm 1 Difference in mean: -1.65 (95% CI: -3.69 to 0.4), p=0.11	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level
O'Donnell, 2018[18]	Arm 1	Control	Psychological well-being	Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being	23	Mean 95.7 (SD 22.4)	6 months	13	Mean 96.7 (SD 31.7)	Mean change from baseline: 4.8 (SD 16.6), p=NR	Comparator: Ref	Baseline
O'Donnell, 2018[18]	Arm 2	Intervention	Psychological well-being	Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being	25	Mean 101 (SD 21.1)	6 months	16	Mean 108.4 (SD 22.1)	Mean change from baseline: 5.2 (SD 31.71), p=NR	Comparator: Arm 1 Difference in mean : NR, p=0.99 SMD: 0.02 (95% CI: -0.72 to 0.74)	Baseline
Rabow, 2004[21, 22]	Arm 1	Control	Overall (20 - 120)	Spiritual Well-Being Scale	40	Mean 95.6 (SD NR)	1 year	40	Mean 92.4 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Overall (20 - 120)	Spiritual Well-Being Scale	50	Mean 94.3 (SD NR)	1 year	50	Mean 105.5 (SD NR)	NR	Comparator: Control p=0.007	Baseline values

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Rabow, 2004[21, 22]	Arm 1	Control	Existential (10 - 60)	Spiritual Well-Being Scale	40	Mean: NR	1 year	40	Mean 44.9 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Existential (10 - 60)	Spiritual Well-Being Scale	50	Mean: NR	1 year	50	Mean 48.2 (SD NR)	NR	Comparator: Control p=0.16	Baseline values
Rabow, 2004[21, 22]	Arm 1	Control	Religious (10 - 60)	Spiritual Well-Being Scale	40	Mean: NR	1 year	40	Mean 46.4 (SD NR)	NR	Comparator: Ref	Baseline values
Rabow, 2004[21, 22]	Arm 2	Intervention	Religious (10 - 60)	Spiritual Well-Being Scale	50	Mean: NR	1 year	50	Mean 55.6 (SD NR)	NR	Comparator: Control p=0.001	Baseline values
Rogers, 2017[23]	Arm 1	UC Alone	Psychological well-being	Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being	74	Mean 118 (SD 25.1)	6 months	40	Mean 125.8 (SD 30.7)	Mean change from baseline: 8.3 (SD 29.1), p=NR	Comparator: Ref p=Ref	Age, sex
Rogers, 2017[23]	Arm 2	UC + PAL	Psychological well-being	Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being	74	Mean 120.6 (SD 27)	6 months	41	Mean 136.5 (SD 28.6)	Mean change from baseline: 16.7 (SD 21.1), p=NR	Comparator: Arm 1 Difference in Mean, at 6 months only: 11.09 (95% CI: 0.19 to 21.99), p=0.0462 SMD (change from baseline): 0.33 (95% CI: -0.17 to 0.77)	Age, sex

AICCP= Advanced Illness Coordinated Care Program; N=sample size; NR=not reported; p=p-value; Ref=reference group; SD=standard deviation.

Table D-26. Concordance between preference and care received categorical outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Events, n(%)	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
O'Donnell, 2018[18]	Arm 1	Usual care	Percentage of patients with improvement in prognostic alignment, defined as revision of patient expectations of prognosis in a direction consistent with those of the treating physician	NR	24	NR	6 months	15	Events: 15 (94)	NR	Comparator: Ref p=Ref	NR
O'Donnell, 2018[18]	Arm 2	Intervention	Percentage of patients with improvement in prognostic alignment, defined as revision of patient expectations of prognosis in a direction consistent with those of the treating physician	NR	26	NR	6 months	16	Events: 4 (26)	NR	Comparator: Arm 1 p< 0.001	NR

N=sample size; NR=not reported; p=p-value; Ref=reference group.

Table D-27. Caregiver reported anxiety continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Events, n(%)	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Dionne-Odom, 2020[9]	Arm 1	Usual Care	Mood-caregiver anxiety	14-item Hospital Anxiety and Depression Scale	76	Mean 3.7 (SD 2.9)	16 weeks	50	Mean 4.2 (SD 0.4)	Mean change from baseline: 0.4 (SE 0.3), p=NR	Comparator: Ref	NR
Dionne-Odom, 2020[9]	Arm 2	Intervention	Mood-caregiver anxiety	14-item Hospital Anxiety and Depression Scale	82	Mean 3.9 (SD 3.1)	16 weeks	32	Mean 3.8 (SD 0.5)	Mean change from baseline: 0.3 (SE 0.3), p=NR	Comparator: Arm 1 Difference in mean: -0.1 (SE 0.5), p=0.88	NR
Kluger, 2020[14]	Arm 1	Standard Care	Anxiety symptoms	Hospital Anxiety and Depression Scale	88	NR	12 months	88	NR	Mean change from baseline: -0.4 (95% CI: -1.13 to 0.34), p=0.29	Comparator: Ref	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Events, n(%)	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Kluger, 2020[14] (continued)	Arm 2	Palliative Care Intervention	Anxiety symptoms	Hospital Anxiety and Depression Scale	87	NR	12 months	87	NR	Mean change from baseline: -0.68 (95% CI: 1.37 to 0.02), p=0.06	Comparator: Arm 1 Difference in mean: -0.43 (95% CI: -1.46 to 0.61), p=0.42	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level

CI=confidence interval; N=sample size; NR=not reported; p=p-value; Ref=reference; SD=standard deviation; SE=standard error.

Table D-28. Caregiver reported caregiver burden continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
O'Riordan, 2019[19]	Arm 1	Usual Care	Caregiver burden-objective	14-item Montgomery-Borgatta Caregiving Burden	76	Mean 20 (SD 2.9)	16 weeks	50	Mean 19.7 (SD 0.4)	Mean change from baseline: -0.1 (SE 0.4), p=NR	Comparator: Ref	NR
O'Riordan, 2019[19]	Arm 2	Intervention	Caregiver burden-objective	14-item Montgomery-Borgatta Caregiving Burden	82	Mean 20.1 (SD 2.8)	16 weeks	32	Mean 20.2 (SD 0.5)	Mean change from baseline: -0.1 (SE 0.4), p=NR	Comparator: Arm 1 Difference in mean: 0 (SE 0.5), p>.99	NR
O'Riordan, 2019[19]	Arm 1	Usual Care	Caregiver burden-demand	14-item Montgomery-Borgatta Caregiving Burden	76	Mean 11.6 (SD 1.8)	16 weeks	50	Mean 11.6 (SD 0.3)	Mean change from baseline: 0.2 (SE 0.3), p=NR	Comparator: Ref	NR
O'Riordan, 2019[19]	Arm 2	Intervention	Caregiver burden-demand	14-item Montgomery-Borgatta Caregiving Burden	82	Mean 11.6 (SD 2.5)	16 weeks	32	Mean 11.1 (SD 0.4)	Mean change from baseline: -0.1 (SE 0.3), p=NR	Comparator: Arm 1 Difference in mean: -0.4 (SE 0.4), p=0.35	NR
O'Riordan, 2019[19]	Arm 1	Usual Care	Caregiver burden-stress	14-item Montgomery-Borgatta Caregiving Burden	76	Mean 12.3 (SD 2.2)	16 weeks	50	Mean 12.2 (SD 0.3)	Mean change from baseline: 0.1 (SE 0.3), p=NR	Comparator: Ref	NR
O'Riordan, 2019[19]	Arm 2	Intervention	Caregiver burden-stress	14-item Montgomery-Borgatta Caregiving Burden	82	Mean 12.3 (SD 2.4)	16 weeks	32	Mean 11.7 (SD 0.4)	Mean change from baseline: -0.3 (SE 0.3), p=NR	Comparator: Arm 1 Difference in mean: -0.4 (SE 0.4), p=0.38	NR

Table D-29. Caregiver reported depression continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Dionne-Odom, 2020[9]	Arm 1	Usual Care	Mood-caregiver depression	14-item Hospital Anxiety and Depression Scale	76	Mean 4.8 (SD 3.3)	16 weeks	50	Mean 4.4 (SD 0.4)	Mean change from baseline: -0.3 (SE 0.3), p=NR	Comparator: Ref	NR
Dionne-Odom, 2020[9]	Arm 2	Intervention	Mood-caregiver depression	14-item Hospital Anxiety and Depression Scale	82	Mean 4.7 (SD 3.1)	16 weeks	32	Mean 4.5 (SD 0.5)	Mean change from baseline: -0.2 (SE 0.4), p=NR	Comparator: Arm 1 Difference in mean: 0.1 (SE 0.5), p=0.86	NR
Kluger, 2020[14]	Arm 1	Standard Care	Depression symptoms	Hospital Anxiety and Depression Scale	88	NR	12 months	88	NR	Mean change from baseline: 0.47 (95% CI: -0.17 to 1.12), p=0.15	Comparator: Ref	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level
Kluger, 2020[14]	Arm 2	Palliative Care Intervention	Depression symptoms	Hospital Anxiety and Depression Scale	87	NR	12 months	87	NR	Mean change from baseline: -0.26 (95% CI: -0.85 to 0.34), p=0.4	Comparator: Arm 1 Difference in mean: -0.9 (95% CI: -1.83 to 0.03), p=0.06	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level

CI=confidence interval; N=sample size; NR=not reported; p=p-value; Ref=reference; SD=standard deviation; SE=standard error.

Table D-30. Caregiver reported psychological continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Kluger, 2020[14]	Arm 1	Standard Care	Psychological well-being	Functional Assessment of Chronic Illness Therapy - Spiritual Wellbeing	88	NR	12 months	88	NR	Mean change from baseline: -0.9 (95% CI: -2.12 to 0.31), p=0.14	Comparator: Ref	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level
Kluger, 2020[14]	Arm 2	Palliative Care Intervention	Psychological well-being	Functional Assessment of Chronic Illness Therapy - Spiritual Wellbeing	87	NR	12 months	87	NR	Mean change from baseline: 0.42 (95% CI: -0.81 to 1.66), p=0.5	Comparator: Arm 1 Difference in mean: 1.79 (95% CI: -0.0 to 3.59), p=0.05	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level

CI=confidence interval; N=sample size; NR=not reported; p=p-value; Ref=reference.

Table D-31. Caregiver reported quality of life continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Dionne-Odom, 2020[9]	Arm 1	Usual Care	Caregiver QOL	15-item Bakas Caregiving Outcomes Scale	76	Mean 60.7 (SD 10.4)	16 weeks	50	Mean 63.9 (SD 1.7)	Mean change from baseline: 1.1 (SE 1.6), p=NR	Comparator: Ref	NR
Dionne-Odom, 2020[9]	Arm 2	Intervention	Caregiver QOL	15-item Bakas Caregiving Outcomes Scale	82	Mean 65 (SD 12.9)	16 weeks	32	Mean 66.9 (SD 2.1)	Mean change from baseline: 0.7 (SE 1.7), p=NR	Comparator: Arm 1 Difference in mean: -0.4 (SE 2.4), p=0.88	NR
Kluger, 2020[14]	Arm 1	Standard Care	Caregiver perspective on patient	Quality of Life Alzheimer's Disease scale	88	NR	12 months	88	NR	Mean change from baseline: -0.76 (95% CI: -1.75 to 0.23), p=0.13	Comparator: Ref	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level
Kluger, 2020[14]	Arm 2	Palliative Care Intervention	Caregiver perspective on patient	Quality of Life Alzheimer's Disease scale	87	NR	12 months	87	NR	Mean change from baseline: 1.81 (95% CI: 0.72 to 2.90), p=0.001	Comparator: Arm 1 Difference in mean: 1.93 (95% CI: 0.51 to 3.36), p=<0.001	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Kluger, 2020[14]	Arm 1	Standard Care	Caregiver burden	Zarit Burden Interview (ZBI-12)	88	Mean 16.8 (NR 7.7)	12 months	88	NR	Mean change from baseline: -0.02 (95% CI: -1.32 to 1.37), p=0.97	Comparator: Ref	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level
Kluger, 2020[14]	Arm 2	Palliative Care Intervention	Caregiver burden	Zarit Burden Interview (ZBI-12)	87	Mean 17.9 (NR 8)	12 months	87	NR	Mean change from baseline: -2.25 (95% CI: -3.56 to -0.94), p=0.001	Comparator: Arm 1 Difference in mean: -2.6 (95% CI: -4.58 to -0.61), p=0.01	Sex, age, disease duration, baseline Montreal Cognitive Assessment score, Hoehn and Yahr stage, study site, and presence of a caregiver, race, marital status, education level

Table D-32. Advance directive documentation continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Engelhardt, 2006[10]	Arm 1	UC	Median time to completion of first AD	NR	142	NA	NA	142	median 238 (SD NR)	NR	Comparator: Ref	NR
Engelhardt, 2006[10]	Arm 2	AICCP	Median time to completion of first AD	NR	133	NA	NA	133	median 46 (SD NR)	NR	Comparator: Arm 1 Difference in medians: 192, p=0.02	NR
Engelhardt, 2006[10]	Arm 1	UC	Mean number of ADs per patient	NR	142	NR	6 months	142	Mean 0.93 (SD 1.07)	NR	Comparator: Ref	NR
Engelhardt, 2006[10]	Arm 2	AICCP	Mean number of ADs per patient	NR	133	NR	6 months	133	Mean 1.33 (SD 0.98)	NR	Comparator: Arm 1 Difference in mean: 0.4, p=0.01	NR

AD=advance directive; AICCP= Advanced Illness Coordinated Care Program; N=sample size; NA=not available; NR=not reported; p=p-value; Ref=reference; SD=standard deviation; UC=usual care.

Table D-33. Advance directive documentation categorical outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup time	Followup N	Patients with Outcomes, n(%)	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Engelhardt, 2006[10]	Arm 1	UC	% of participant who had completed at least 1 AD	NR	142	NR	6 months	142	Patients: 69 (48.4)	NR	Comparator: Ref	NR
Engelhardt, 2006[10]	Arm 2	AICCP	% of participant who had completed at least 1 AD	NR	133	NR	6 months	133	Patients: 99 (69.4)	NR	Comparator: Arm 1 p=0.006, RR: 0.65 (95% CI: 0.54 to 0.79)	NR
Engelhardt, 2009[11]	Arm 1	Usual Care	Advance directive documentation	NR	194	Patients: 0 (0)	NR	194	Patients: 41 (21.1)	NR	Comparator: Ref	NR
Engelhardt, 2009[11]	Arm 2	AICCP	Advance directive documentation	NR	166	Patients: 0 (0)	NR	166	Patients: 78 (47)	NR	Comparator: Arm 1 p< 0.001, RR: 0.45 (95% CI: 0.33 to 0.62)	NR
Feely, 2016[12]	Overall	All	Advance directive documentation	NR	92	Patients: 38 (41)	NR	92	Patients: 42 (46)	NR	NA	NR
Goldstein, 2019[13]	Arm 1	Standard Care	Advance directive documentation	NR	224	Patients: 61 (52.6)	24 months	61	Patients: 61 (52.6)	NR	Comparator: Ref	NR
Goldstein, 2019[13]	Arm 2	WISDOM	Advance directive documentation	NR	301	Patients: 106 (57.9)	24 months	106	Patients: 106 (57.9)	NR	Comparator: Arm 1 p=0.37	NR
Kluger, 2020[14]	Arm 1	Standard Care	Advance directive completion	NR	104	Patients: 68 (65.38)	6 months	31	Patients: 8 (26)	NR	Comparator: Ref	NR
Kluger, 2020[14]	Arm 2	Palliative Care Intervention	Advance directive completion	NR	106	Patients: 61 (57.55)	6 months	38	Patients: 20 (53)	NR	Comparator: Arm 1 p=0.02 RR: 0.49 (95% CI: 0.25 to 0.96)	NR

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup time	Followup N	Patients with Outcomes, n(%)	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Kluger, 2020[14]	Arm 1	Standard Care	Health care proxy completion	NR	104	Patients: 77 (74.04)	6 months	23	Patients: 9 (39)	NR	Comparator: Ref	NR
Kluger, 2020[14]	Arm 2	Palliative Care Intervention	Health care proxy completion	NR	106	Patients: 78 (73.58)	6 months	33	Patients: 11 (33)	NR	Comparator: Arm 1 p=0.55 RR: 1.17 (95% CI: 0.58 to 2.37)	NR
O'Donnell, 2018[18]	Arm 1	Usual care	% of any documentation of ACP	NR	24	Patients: 4 (16.6)	6 months6 months	24	Patients: 8 (33)	NR	Comparator: Ref	NR
O'Donnell, 2018[18]	Arm 2	Intervention	% of any documentation of ACP	NR	26	Patients: 4 (15.4)	6 months6 months	26	Patients: 17 (65)	NR	Comparator: Arm 1 p=0.02, RR: 0.33 (95% CI: 0.13 to 0.88)	NR
O'Donnell, 2018[18]	Arm 1	Usual care	% of physician-level documentation of ACP	NR	24	NR	6 months6 months	24	Patients: 5 (20)	NR	Comparator: Ref	NR
O'Donnell, 2018[18]	Arm 2	Intervention	% of physician-level documentation of ACP	NR	26	NR	6 months6 months	26	Patients: 15 (58)	NR	Comparator: Arm 1 p=0.1, RR: 0.36 (95% CI: 0.15 to 0.84)	NR
O'Riordan, 2019[19]	Arm 1	Usual Care	Advance care planning documentation and completed POLST form	NR	14	NR	6 months6 months	14	Patients: 3 (21.4)	NR	Comparator: Ref	NR
O'Riordan, 2019[19]	Arm 2	PC Intervention	Advance care planning documentation and completed POLST form	NR	16	NR	6 months	16	Patients: 8 (50)	NR	Comparator: Arm 1 p=0.15 RR: 0.43 (95% CI: 0.14 to 1.31)	NR

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup time	Followup N	Patients with Outcomes, n(%)	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Rabow, 2004[21, 22]	Arm 1	Control	% of patients with DPOA-HC paperwork	NR	40	Patients: 16 (40)	1 year	40	Patients: 21 (52.5)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	% of patients with DPOA-HC paperwork	NR	50	Patients: 19 (38)	1 year	50	Patients: 31 (62)	NR	Comparator: Arm 1 p=0.12, RR: 0.52 (95% CI: 0.20 to 1.36)	NR

ACP=advance care planning; AD=advance directive; AICCP=Advanced Illness Coordinated Care Program; CI=confidence interval; DPOA-HC=Durable Power of Attorney for Health Care; N=sample size; NR=not reported; p=p-value; PC=palliative care; POLST=Portable Medical Orders; Ref=reference group; RR=relative risk; UC=usual care; WISDOM=Working to Improve discuSsions About DefibrillatOr Management.

Table D-34. Cost and resource use continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Engelhardt, 2006[10]	Arm 1	UC	Healthcare cost of patients by treatment	NR	142	Mean 19701.95 (SD 24492.43)	6 months	142	Mean 16295.46 (SD 28491.71)	Mean change from baseline: 7777.2 (SD 14629.68), p=Ref	Comparator: Ref	NR
Engelhardt, 2006[10]	Arm 2	AICCP	Healthcare cost of patients by treatment	NR	133	Mean 17678.19 (SD 16478.08)	6 months	133	Mean 12123.37 (SD 16036.13)	Mean change from baseline: 4352.78 (SD 5660.47), p=0.365	Comparator: Arm 1 Difference in mean: 4172.09, p=0.2894 Calculated Mean between group difference: -3424.42 (95% CI: -13519.98 to 6671.14)	NR
Engelhardt, 2009[11]	Arm 1	Usual Care	ED visits	NR	NR	Mean 2.4 (SD 4.17)	NR	NR	Mean 5.35 (SD 12.87)	NR	Comparator: Ref	Baseline score, age, sex
Engelhardt, 2009[11]	Arm 2	AICCP	ED visits	NR	NR	Mean 2.01 (SD 2.88)	NR	NR	Mean 3.69 (SD 6.14)	NR	Comparator: Arm 1 p=NS	Baseline score, age, sex
Engelhardt, 2009[11]	Arm 1	Usual Care	Radiology tests	NR	NR	Mean 3.76 (SD 5.09)	NR	NR	Mean 3.89 (SD 10.38)	NR	Comparator: Ref	Baseline score, age, sex
Engelhardt, 2009[11]	Arm 2	AICCP	Radiology tests	NR	NR	Mean 4.12 (SD 5.4)	NR	NR	Mean 3.13 (SD 6.85)	NR	Comparator: Arm 1 p=NS	Baseline score, age, sex
Engelhardt, 2009[11]	Arm 1	Usual Care	Outpatient visits	NR	NR	Mean 32.21 (SD 23.67)	NR	NR	Mean 29.42 (SD 25.52)	NR	Comparator: Ref	Baseline score, age, sex
Engelhardt, 2009[11]	Arm 2	AICCP	Outpatient visits	NR	NR	Mean 32.41 (SD 20.71)	NR	NR	Mean 32.01 (SD 25.05)	NR	Comparator: Arm 1 p=NS	Baseline score, age, sex

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Engelhardt, 2009[11]	Arm 1	Usual Care	Laboratory tests	NR	NR	Mean 169.57 (SD 228.88)	NR	NR	Mean 200.35 (SD 276.98)	NR	Comparator: Ref	Baseline score, age, sex
Engelhardt, 2009[11]	Arm 2	AICCP	Laboratory tests	NR	NR	Mean 162.14 (SD 204.62)	NR	NR	Mean 217.91 (SD 327.58)	NR	Comparator: Arm 1 p=NS	Baseline score, age, sex
Engelhardt, 2009[11]	Arm 1	Usual Care	Home health visits	NR	NR	Mean 2.23 (SD 5.88)	NR	NR	Mean 3.55 (SD 14.15)	NR	Comparator: Ref	Baseline score, age, sex
Engelhardt, 2009[11]	Arm 2	AICCP	Home health visits	NR	NR	Mean 2.86 (SD 9.02)	NR	NR	Mean 4.67 (SD 13.12)	NR	Comparator: Arm 1 p=NS	Baseline score, age, sex
Engelhardt, 2009[11]	Arm 1	Usual Care	Pharmacy prescriptions	NR	NR	Mean 59.19 (SD 44.22)	NR	NR	Mean 64.22 (SD 48.56)	NR	Comparator: Ref	Baseline score, age, sex
Engelhardt, 2009[11]	Arm 2	AICCP	Pharmacy prescriptions	NR	NR	Mean 65.41 (SD 51.62)	NR	NR	Mean 69.89 (SD 52.06)	NR	Comparator: Arm 1 p=NS	Baseline score, age, sex
Lakin, 2020[15-17]	Arm 1	Compariso n										
Lakin, 2020[15-17]	Arm 2	Integrated Care Program										
Owens, 2012[20]	Overa ll	Overall	Mean ED visits/week	NR	49	Mean 0.0677 (SD 0.0848)	2010	49	Mean 0.0412 (SD 0.108)	p=0.001	NA	NR
Rabow, 2004[21, 22]	Arm 1	Control	Clinic visits	NR	40	NR	1 year	40	Mean 10.6 (SD 7.5)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	Clinic visits	NR	50	NR	1 year	50	Mean 7.5 (SD 4.9)	NR	Comparator: Arm 1 p=0.03	NR

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Rabow, 2004[21, 22]	Arm 1	Control	Urgent care visits	NR	40	NR	1 year	40	Mean 0.6 (SD 0.9)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	Urgent care visits	NR	50	NR	1 year	50	Mean 0.3 (SD 0.5)	NR	Comparator: Arm 1 p=0.04	NR
Rabow, 2004[21, 22]	Arm 1	Control	Specialist visits	NR	40	NR	1 year	40	Mean 7 (SD 9.1)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	Specialist visits	NR	50	NR	1 year	50	Mean 4.9 (SD 8.1)	NR	Comparator: Arm 1 p=0.25	NR
Rabow, 2004[21, 22]	Arm 1	Control	ED visits	NR	40	NR	1 year	40	Mean 1.7 (SD 2.8)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	ED visits	NR	50	NR	1 year	50	Mean 1.6 (SD 2.2)	NR	Comparator: Arm 1 p=0.81	NR
Rabow, 2004[21, 22]	Arm 1	Control	All medical center services	NR	40	NR	1 year	40	Mean 43338 (SD 69647)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	All medical center services	NR	50	NR	1 year	50	Mean 47211 (SD 73009)	NR	Comparator: Arm 1 p=0.8	NR
Rabow, 2004[21, 22]	Arm 1	Control	Clinic visit charges	NR	40	NR	1 year	40	Mean 8068 (SD 9055)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	Clinic visit charges	NR	50	NR	1 year	50	Mean 7311 (SD 10880)	NR	Comparator: Arm 1 p=0.73	NR

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Rabow, 2004[21, 22]	Arm 1	Control	Urgent care visits charges	NR	40	NR	1 year	40	Mean 1342 (SD 2909)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	Urgent care visits charges	NR	50	NR	1 year	50	Mean 749 (SD 2210)	NR	Comparator: Arm 1 p=0.29	NR
Rabow, 2004[21, 22]	Arm 1	Control	ED visits charges	NR	40	NR	1 year	40	Mean 1313 (SD 3281)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	ED visits charges	NR	50	NR	1 year	50	Mean 754 (SD 1138)	NR	Comparator: Arm 1 p=0.32	NR
Rabow, 2004[21, 22]	Arm 1	Control	Inpatient services charges	NR	40	NR	1 year	40	Mean 31225 (SD 66611)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	Inpatient services charges	NR	50	NR	1 year	50	Mean 31294 (SD 54285)	NR	Comparator: Arm 1 p=0.1	NR
Rabow, 2004[21, 22]	Arm 1	Control	Other charges	NR	40	NR	1 year	40	Mean 1427 (SD 4714)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	Other charges	NR	50	NR	1 year	50	Mean 1619 (SD 7973)	NR	Comparator: Arm 1 p=0.89	NR

AD=advanced director; AICCP=Advanced Illness Coordinated Care Program; CI=confidence interval; ED=emergency department; N=sample size; NA=not available; NR=not reported; NS=non-significant; p=p-value; Ref=reference group; SD=standard deviation.

Table D-35. Hospitalization continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Engelhardt, 2009[11]	Arm 1	Usual Care	Inpatient admissions	NR	NR	Mean 2.19 (SD 5.95)	NR	NR	Mean 4.33 (SD 16.26)	NR	Comparator: Ref	Baseline score, age, sex
Engelhardt, 2009[11]	Arm 2	AICCP	Inpatient admissions	NR	NR	Mean 1.97 (SD 3.35)	NR	NR	Mean 2.44 (SD 5.11)	NR	Comparator: Arm 1 p=NS	Baseline score, age, sex
Goldstein, 2019[13]	Arm 1	Standard Care	# of hospital admissions	NR	224	NR	24 months	224	Mean 1.2 (SD 1.8)	NR	Comparator: Ref	NR
Goldstein, 2019[13]	Arm 2	WISDOM	# of hospital admissions	NR	301	NR	24 months	301	Mean 1.4 (SD 1.9)	NR	Comparator: Arm 1 p=0.13	NR
Goldstein, 2019[13]	Arm 1	Standard Care	# of days in the hospital	NR	224	NR	24 months	224	Mean 15.9 (SD 33)	NR	Comparator: Ref	NR
Goldstein, 2019[13]	Arm 2	WISDOM	# of days in the hospital	NR	301	NR	24 months	301	Mean 16.1 (SD 26)	NR	Comparator: Arm 1 p=0.93	NR
Rabow, 2004[21, 22]	Arm 1	Control	Hospital admissions	NR	40	NR	1 year	40	Mean 0.8 (SD 1)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	Hospital admissions	NR	50	NR	1 year	50	Mean 1.2 (SD 2)	NR	Comparator: Arm 1 p=0.21	NR
Rabow, 2004[21, 22]	Arm 1	Control	Total hospital days	NR	40	NR	1 year	40	Mean 4.3 (SD 9)	NR	Comparator: Ref	NR
Rabow, 2004[21, 22]	Arm 2	Intervention	Total hospital days	NR	50	NR	1 year	50	Mean 6.3 (SD 12.4)	NR	Comparator: Arm 1 p=0.38	NR
Rogers, 2017[23]	Arm 1	UC Alone	6 months rehospitalization for heart failure	NR	75	NR	6 months	75	Mean 50 (SD unclear)	NR	Comparator: Arm 1 Difference in mean: 50p=unclear	NR
Rogers, 2017[23]	Arm 2	UC + PAL	6 months rehospitalization for heart failure	NR	75	NR	NR	75	53 (SD unclear)	NR	Comparator: Arm 2 Difference in mean: 53, p=NR	NR

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Rogers, 2017[23]	Arm 1	UC Alone	6 months rehospitalization for non-heart failure cardiovascular	NR	75	NR	NR	NR	NR	NR	NR	NR
Rogers, 2017[23]	Arm 2	UC + PAL	6 months rehospitalization for non-heart failure cardiovascular	NR	75	NR	NR	NR	NR	NR	NR	NR
Rogers, 2017[23]	Arm 1	UC Alone	6 months rehospitalization for noncardiovascular	NR	75	NR	NR	NR	NR	NR	NR	NR
Rogers, 2017[23]	Arm 2	UC + PAL	6 months rehospitalization for noncardiovascular	NR	75	NR	NR	NR	NR	NR	NR	NR

AD=advance directive; AICCP=Advanced Illness Coordinated Care Program; CI=confidence interval; ED=emergency department; N=sample size; NR=not reported; NS=non-significant; p=p-value; PAL= palliative care intervention; Ref=reference group; SD=standard deviation; UC=usual care; WISDOM=Working to Improve discuSsions About DefibrillatOr Management.

Table D-36. Hospitalization categorical outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Patients with Outcomes, n(%)	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Bekelman, 2018[8]	Arm 1	Usual care	# of individal with one hospitalization	NR	157	NR	6 months	157	Patients: 30 (19.11)	NR	Comparator: Ref	NR
Bekelman, 2018[8]	Arm 2	CASA	# of individal with one hospitalization	NR	157	NR	6 months	157	Patients: 18 (11.46)	NR	Comparator: Arm 1 p=0.61, RR: 0.6 (95% CI: 0.35 to 1.03)	NR
Bekelman, 2018[8]	Arm 1	Usual care	# of indivdiual with 2+ hospitalization	NR	157	NR	6 months	157	Patients: 6 (3.82)	NR	Comparator: Ref	NR
Bekelman, 2018[8]	Arm 2	CASA	# of indivdiual with 2+ hospitalization	NR	157	NR	6 months	157	Patients: 9 (5.73)	NR	Comparator: Arm 1 p=0.61, RR: 1.5 (95% CI: 0.55 to 4.11)	NR
Bekelman, 2015[7]	Arm 1	Usual Care	1 year hospitalization rate	NR	197	NR	1 year	NR	Patients: NR (29.9)	NR	Comparator: Ref	NR
Bekelman, 2015[7]	Arm 2	Intervention	1 year hospitalization rate	NR	187	NR	1 year	NR	Patients: NR (29.4)	NR	Comparator: Arm 1 p=0.87	NR
Rogers, 2017[23]	Arm 1	UC Alone	6 months rehospitalization for heart failure	NR	75	NR	6 months	75	Patients: 22 (29.3)	NR	Comparator: Ref	NR
Rogers, 2017[23]	Arm 2	UC + PAL	6 months rehospitalization for heart failure	NR	75	NR	6 months	75	Patients: 23 (30.7)	NR	Comparator: Arm 1 RR: 1.05 (95% CI: 0.64 to 1.7)	NR
Rogers, 2017[23]	Arm 1	UC Alone	6 months rehospitalization for non-heart failure cardiovascular	NR	75	NR	6 months	75	Patients: 10 (13)	NR	Comparator: Ref	NR
Rogers, 2017[23]	Arm 2	UC + PAL	6 months rehospitalization for non-heart failure cardiovascular	NR	75	NR	6 months	75	Patients: 12 (16)	NR	Comparator: Arm 1 RR: 1.2 (95% CI: 0.55 to 2.61)	NR
Rogers, 2017[23]	Arm 1	UC Alone	6 months rehospitalization for noncardiovascular	NR	75	NR	6 months	75	Patients: 18 (24)	NR	Comparator: Ref	NR
Rogers, 2017[23]	Arm 2	UC + PAL	6 months rehospitalization for noncardiovascular	NR	75	NR	6 months	75	Patients: 8 (10.7)	NR	Comparator: Arm 1 RR: 0.44 (95% CI: 0.21 to 0.96)	NR

CASA=Collaborative Care to Alleviate Symptoms and Adjust to Illness; CI=confidence interval; N=sample size; NR=not reported; p=p-value; Ref=reference group; PAL= palliative care intervention; RR=relative risk; UC=usual care.

Table D-37. Use and length of hospice care continuous outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Lakin, 2017[15-17]	Arm 1	Comparison	Length of hospice stay	NR	27	NA	NR	27	Mean 29.3 (SD NR)	NR	Comparator: Ref	NR
Lakin, 2017[15-17]	Arm 2	Integrated Care Program	Length of hospice stay	NR	47	NA	NR	47	Mean 51 (SD NR)	NR	Comparator: Arm 1 p=0.43	NR
Lakin, 2020[15-17]	Arm 1	Comparison	End of life spending from Medicare claims data, total medical expense (TME) paid to provider for medical care per member per month over the last year	NR	40	Mean 4476 (95% CI: 2640-6313)	Last 1 month of life	40	Mean 13563 (95% CI: 7936-19190)	NR	Comparator: Ref	NR
Lakin, 2020[15-17]	Arm 2	Integrated Care Program	End of life spending from Medicare claims data, total medical expense (TME) paid to provider for medical care per member per month over the last year	NR	84	Mean 4006 (95% CI: 2799-5213)	Last 1 month of life	84	Mean 12602 (95% CI: 9145-16059)	NR	Comparator: Arm 1 Difference in mean: 961 (SD: NR), p=0.77	NR

CI=confidence interval; N=sample size; NR=not reported; p=p-value; Ref=reference group; SD=standard deviation.

Table D-38. Use and length of hospice care categorical outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Followup Results	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Lakin, 2017[15-17]	Arm 1	Comparison	% use of hospice in last 6 months of life	NR	27	NA	NR	27	Patients: 11 (40.7)	NR	Comparator: Ref	NR
Lakin, 2017[15-17]	Arm 2	Integrated Care Program	% use of hospice in last 6 months of life	NR	47	NA	NR	47	Patients: 26 (55.3)	NR	Comparator: Arm 2 % of patient who died who used hospice at least for one day in th last 6 months: 14.6 (SD NR), p=0.3342 Calculated RR: 1.36 (95% CI: 0.81 to 2.29)	NR

CI=confidence interval; N=sample size; NA=not available; NR=not reported; p=p-value; Ref=reference group; RR=relative risk; SD=standard deviation.

Table D-39. Dropouts categorical outcomes for studies comparing effectiveness of models or multimodal interventions for integrating palliative care for patients with serious life-threatening chronic illness or conditions in ambulatory settings.

Author, Year	Arm	Treatment	Outcome Detail	Tool Used to Measure Outcome	Baseline N	Baseline Results	Followup Time	Followup N	Patients with Outcomes, n(%)	Within-arm Comparison	Between-arm Comparison	Adjusted Factors
Rabow, 2004[21, 22]	Arm 1	Control	Dropouts	NR	1 year	NR	NR	NA	Patients: 40 (9)	NA	Comparator: Ref	NA
Rabow, 2004[21, 22]	Arm 2	Intervention	Dropouts	NR	1 year	NR	NR	NA	Patients: 50 (15)	NA	Comparator: Arm 1 RR: 1.33 (95% CI: 0.64 to 2.72)	NA

CI=confidence interval; N=sample size; NA=not available; NR=not reported; p=p-value; Ref=reference group; RR=relative risk.

Table D-40. Summary of study characteristics for qualitative review

Key Question	Author, Year	Study Qualitative/Implementation Objective(s)	Qualitative Data Collection Method (interviews, focus groups, ethnographies, other)	Qualitative Data Analysis Method (constant comparative, thematic, narrative, other)
3c	Dillon, 2017[26]	To understand how providers incorporate electronic health record ACP documentation into clinical practice	Interviews	Thematic analysis
3c	Metzger, 2016[31]	To describe LVAD patients' and surrogates' experiences with, and perspectives on SPIRIT-HF, an advance care planning (ACP) intervention	Interviews	They state (p. 307): "qualitative content analysis techniques" -- though generally seems like: Thematic analysis – secondary analysis of interviews
3c	O'Hare, 2016[39]	To gain insight from providers from a range of disciplines and specialties who care for patients with advanced kidney disease to identify potential opportunities to enhance ACP for this population.	Interviews	Authors describe as "grounded theory", but seems more appropriately described as thematic analysis
3c	Song, 2017[36]	To explore the perspectives of the bereaved surrogates of dialysis patients on the process and impact of an advance care planning intervention and to compare the perceived impacts of the intervention between African Americans and Whites	Interviews	Thematic analysis
3c	Uhler, 2015[37]	To assess the usability of the InformedTogether decision aid	Other: Qualitative Observations	Thematic analysis
4c	Paladino, 2019[33]	To evaluate whether a novel train-the-trainer model results in high-quality training that improves clinicians' self-reported competencies in serious illness communication	Other: Text analysis	Thematic content analysis
5c	Bekelman, 2011[40]	To learn about patients' and their family caregivers' major concerns and needs and to explore whether and how palliative care would be useful to them.	Interviews	Constant Comparison derived from grounded theory
5c	Bekelman, 2014[24]	To determine the feasibility and acceptability of CASA (Collaborative Care to Alleviate Symptoms and Adjust to Illness) and identify necessary improvements	Interviews	Thematic analysis
5c	Bekelman, 2016[25]	To understand organizational factors that could influence the adoption and scale-up of outpatient palliative care in chronic advanced illness, using the example of heart failure	Interviews	Thematic analysis
5c	Goff, 2019[27]	To identify barriers and facilitators for implementation of "Shared Decision Making and Renal Supportive Care" (SDM-RSC), an intervention to improve advance care planning (ACP) for patients with ESKD on hemodialysis	Other: Observations and open-ended survey questions	Thematic analysis
5c	Hobler, 2018[28]	To identify palliative care and advance care planning needs of patients with CF and their families and to identify clinicians' potential roles in meeting these needs.	Interviews	Modified grounded theory approach
5c	Lakin, 2019[29]	To explore the perceptions of primary care clinicians about interprofessional work in serious illness communication	Interviews	Thematic analysis
5c	Long, 2014[30]	To evaluate the feasibility and usefulness of an advance practice nurse delivered palliative care intervention in patients with symptomatic COPD	Interviews	Directed content analysis
5c	Nowels, 2016[32]	To explore primary care providers' willingness and perceived capacity to provide basic palliative care, and their concerns and perceived barriers	Interviews	Thematic analysis

Key Question	Author, Year	Study Qualitative/Implementation Objective(s)	Qualitative Data Collection Method (interviews, focus groups, ethnographies, other)	Qualitative Data Analysis Method (constant comparative, thematic, narrative, other)
5c	Rabow, 2003[34]	To explore perceptions of the acceptability and benefits of the CCT intervention	Interviews	Thematic analysis
5c	Scherer, 2018[35]	Development of outpatient integrated nephrology and palliative care program	Interviews	Thematic analysis

ACP=advanced care panning; CASA=Collaborative Care to Alleviate Symptoms and Adjust to Illness; CCT=interdisciplinary consultation team; CF=cystic fibrosis; COPD= Chronic obstructive pulmonary disease; ESKD=end stage kidney disease; LVAD=Left Ventricular Assist Device; SDM-RSC=Shared Decision Making and Renal Supportive Care; SPIRIT-HF=Sharing the Patient's Illness Representations to Increase Trust in Heart Failure.

Table D-41. Results for qualitative review

Author, Year	Themes/Subthemes Identified Relevant to the KQ	Conclusions	Linked to Effectiveness Data
Dillon, 2017[26]	1. Advance directives are vague, and providers find POLST forms more useful for seriously ill patients owing to the level of specificity and detail. 2. The provider who sees the patient the most frequently and has a relationship with them should be responsible for advance care planning. 3. Lack of interoperability between inpatient and outpatient EHR platforms was a major barrier to documenting ACP; some providers felt time and lack of education about ACP were barriers to doing ACP. 4. Facilitators to ACP documentation were having trusting patient-physician relationships, standardized workflows, education for providers, policy changes facilitating a registry, and a "quarterback" take ownership.	Need for: improved interoperability between hospital and outpatient EHR systems, ownership and consensus of which provider should document ACP, and standardized clinic workflows for ACP documentation.	No
Nowels, 2016[32]	1. Providers felt palliative care should be provided to terminally ill patients or patients in preterminal stages to provide patient and family support. 2. Providers typically addressed physical and emotional symptoms of patients but did not often perform a spiritual assessment or engage in goals of care conversations owing to patient/family resistance in acknowledging declining health status. Providers agreed they should manage all or most palliative needs, but several practices delegated to other team members such as SW 3. Providers did not feel they were delivering palliative care, but rather supportive care 4. Providers described very little community palliative care availability but could refer to hospice 5. Providers felt a patient registry, a multidimensional needs assessment, decision aids, and support for care management would help facilitate PC; coaches were helpful for some providers 6. PC needs to be financially supported and prioritized by practices	Systematic attention along the multidimensional domains of basic palliative care may enable practices to address the unmet needs of patients with complex illnesses by using existing practice improvement models, strategies, and prioritization.	No
Scherer, 2018[35]	1. Stakeholder needs; subthemes: clinical, operational, and institutional/community 2. Challenges to meet stakeholder needs; subthemes: misconception of palliative care, need for clarification of collaborative care, and apprehension concerning practice change	Creation of shared ownership can facilitate innovation and practice change	No

Author, Year	Themes/Subthemes Identified Relevant to the KQ	Conclusions	Linked to Effectiveness Data
Uhler, 2015[37]	1. Although patients and doctors found InformedTogether acceptable and would recommend that doctors use the decision aid with COPD patients, many patients had difficulty understanding the icon arrays that were used to communicate estimated prognoses and could not articulate the definitions of the two treatment choices—Full Code and Do Not Resuscitate (DNR). 2. Minor usability problems regarding content, links, layout, and consistency were also identified and corresponding recommendations were outlined. In particular, participants suggested including more information about potential changes in quality of life resulting from the alternative advance directives. 3. Some doctor participants thought the decision aid was too long and some thought it may cause nervousness among patients owing to the topic area.	InformedTogether decision aid found acceptable to most COPD patients and doctors. Many patients did not demonstrate understanding of treatment options or prognostic estimates. Patients desired more information on changes in quality of life from the alternative ADs.	No
Paladino, 2019[33]	1. Scripting was helpful for speed, to allow conversation to flow better, and to take time to appreciate fears and goals 2. Helped clinicians learn to initiate the conversation, to “listen more, talk less” 3. Clinicians reported that they shouldn’t “let my own worries deter me” as the conversation is very important; paradigm shift from focus on getting a DNR to exploring the questions with patients 4. Clinicians felt more comfortable approaching discussion after training **“Inquire from patients about their world and illness experience”**	Serious illness communication training, delivered through a train-the-trainer model, was highly acceptable and resulted in significant self-reported improvements in competencies of clinicians.	In article -- Yes – Lakin, 2017[8]
Bekelman, 2014[24]	1. Majority of patients reported a positive experience with the nursing component as a “good source of information” regarding lifestyle changes and self-monitoring and found it helpful for self-care. Nurse was also an “advocate,” “someone in my corner” 2. Majority of patients satisfied with phone call structure of the program owing to flexibility and thought intervention should be provided after diagnosis 3. Phone symptom surveys were burdensome and repetitive; grief and loss module not relevant for all patients, as they were not depressed	CASA intervention is feasible and perceived as helpful by participants, based on participant enrollment, cohort retention, implementation of medical recommendations, minimal missing data, and acceptability.	Yes – Bekelman, 2018[8]

Author, Year	Themes/Subthemes Identified Relevant to the KQ	Conclusions	Linked to Effectiveness Data
Bekelman, 2016[25]	In order to adopt and scale up outpatient palliative care, there is a need to: 1. Develop performance measures for patient-centered care and outcomes that can be used to measure the quality and incentivize the spread of outpatient palliative care 2. Justify additional personnel costs, such as with evidence the costs are offset by other savings or with improvements in patient outcomes and primary care staff workflow. Assess and address practical issues such as staffing and space prior to implementation. 3. Communicate and coordinate with other providers, particularly primary care providers, to maximize buy-in. The nature of communication and coordination (e.g., by phone, through the electronic health record) should be tailored to local and individual preferences. 4. Collaborate with local leaders to determine how outpatient palliative care aligns with local programs (e.g., primary care (PACT), telehealth, mental health, home-based primary care) and needs (e.g., documentation of life-sustaining treatment preferences, referral to and management of patients in hospice) 5. Clarify the roles and responsibilities of outpatient palliative care vs. primary and specialty care for disease management in advanced chronic illnesses such as heart failure. Structure core components of outpatient palliative care to allow for flexibility during implementation	The combination of policy changes to create incentives and collaboration with local VHA providers and leaders is important in the adoption and scale-up of outpatient palliative care.	No
Lakin, 2019[29]	1. **Interprofessional teamwork drives serious illness communication** – different views held by members of each of the professions came together to strengthen the output of serious illness conversations; nurses are the champions and leaders of serious illness communication in the case management setting by helping organize tasks, prioritize roles, and remove workflow barriers in a way that enabled serious illness conversations; every clinician has responsibility to take initiative in executing serious illness conversations 2. A **conversation is not just a conversation – conversations require multiple levels of preparation, structure helps serious illness communication;** personal preparation for the conversation, preparing the environment where the meeting will happen, and preparing the patient/family prior to the conversation; a programmatic approach to conversation ensured they systematically/consistently addressed end-of-life care and goals 3. R**elieving some problems reveals other problems –** lack of clear roles led to missed opportunities to utilize other professional's expertise; well established relationships within the interdisciplinary team, and with patients improved serious illness communication; explicit care plans following the conversation helped ensure appropriate action (i.e., lack of clarity may result in aggressive treatment that the patient didn't want)	Three key areas of focus for improving serious illness conversations by interprofessional primary care teams: 1- establishing clear professional roles and responsibilities, 2- paying special attention to interprofessional and clinician-patient relationships, and 3- clearly structuring interventions aiming to change the way our system drives serious illness communication.	Yes – Lakin, 2017[8]

Author, Year	Themes/Subthemes Identified Relevant to the KQ	Conclusions	Linked to Effectiveness Data
Hobler, 2018[28]	Three domains of palliative care needs were identified: 1. To be listened to, feel heard, and be "seen" 2. Understanding the context around CF and its trajectory to help with future planning and preparation 3. Information about and potential solutions to circumstances that can cause stress	Patients expressed a need for and openness to palliative care services, as well as some reluctance. They appreciated clinician communication that was open, forthcoming, and attuned to individualized concerns.	No
Long, 2014[30]	1. **Improved QoL:** The intervention improved QOL by helping with breathing, building self-confidence, recovering more quickly from SOB, and being more active. Feelings of depression resolved after SOB resolved with opioids 2. **Issues around study participation:** The majority of participants liked the intervention and didn't suggest changes. Some participants wanted the questionnaires to be more specific to COPD conditions, wanted the intervention to be longer, and addressed "inappropriate" questions about sex and COPD. All liked working with the advanced practice nurse and the majority wanted to continue receiving palliative care. Driving to the clinic was a barrier and recommended coordinating study visits with other clinic visits to ease the burden of travel to clinic. Concerns about taking opioids and cost of paying for pulmonary rehab and PC clinic visits influenced their decision to continue PC after the close of the study 3. **Managing expectation:** Six participants (46%) talked about how their results from treatment were ''nothing drastic'' and ''slow coming'' and ''didn't make enough improvement to continue.'' Two said they did not know what to expect early in the study. One said she had been under the impression the study would pay for pulmonary rehabilitation.	Participants reported subjective benefit from palliative care, and the intervention was feasible.	No

Author, Year	Themes/Subthemes Identified Relevant to the KQ	Conclusions	Linked to Effectiveness Data
Rabow, 2003[34]	1. The CCT intervention was acceptable to patients who were still actively seeking disease treatment. The majority of the patients would have wanted the intervention even earlier in the course of their illness and none reported that they would have wanted it later. The interdisciplinary team was well received by patients. They appreciated the intervention's attention to difficult/personal topics such as advanced care planning discussions (even though these discussions were difficulty/uncomfortable to the majority) or spirituality, 2. Most patients perceived that the CCT intervention improved their sense of connection/satisfaction with caregivers, provided instrumental support, decreased healthcare utilization, improved spiritual well-being, and helped people provide care to other sicker members of their own family, 3. All patients reported feeling cared for, valued, listened or receiving compassionate care from CCT. Many reported improved communication and increased sense of connection with their PCP, with family members, and with the medical center 4. The CCT intervention led to improved satisfaction in relationships with family members, their PCP, and the medical center as a whole, 5. Some patients said involvement in the CCT enabled them to avoid at least one ED visit, hospitalization, PCP, or pharmacy, 6. Many participants served as the primary family caregiver for an even more seriously ill relative – they reported their CCT palliative care education helped them care for their loved ones .	Development of a dedicated, interdisciplinary team of providers and volunteers may be beyond the capabilities of some health care institutions. However, some simple and relatively inexpensive components of such an intervention appear to be effective and may be offered by non-medical personnel. These include obtaining social services that patients already qualify for under existing funding mechanisms, facilitating better communication about difficult issues, and offering patients the simple gift of listening with compassion. Patients at the beginning of the end of life want these interventions even earlier in the course of their illness than we might expect. Introducing patients to palliative care philosophy, services, and techniques in the outpatient setting, prior to the drama of hospitalized dying, may provide an opportunity for growth, as well as clarification of the seeming paradox between simultaneously wishing to forestall and needing to prepare for death.	Yes - Rabow, 2004[21]
Metzger, 2016[31]	1. Sharing the story of their HF (or caregiver telling story) was a positive and essential part of the experience – helped lay the foundation for the rest of the conversation related to end-of-life care; helped reinforce the surrogate decision maker's experience and perspective, 2. The intervention brought patients and surrogates increased peace of mind – allowed them to express or clarify their wishes, be more prepared for the "what-ifs,"and have a clearer idea of what outcomes of medical treatments would be unacceptable to the patient. Surrogates felt armed with increased knowledge that increased their preparedness for end of life, 3. Advance care planning discussions should take an individualized approach and best timing may vary by person – most surrogates recommended having the conversation before the procedure while some patients suggested waiting until after LVAD placement.	Elements of the intervention, such as including both patients and surrogates, inviting both groups to share their HF stories, focusing on outcomes of treatment options, and beginning or continuing the discussions during a time of relative medical stability, were characterized as particularly important to participants. Because many of the aspects of the intervention listed above are not resource intensive, discipline- or illness-specific, or particularly time-consuming, they could readily be incorporated into patient care, by the clinicians who know the patient best.	Yes – but not included in our references[34]

Author, Year	Themes/Subthemes Identified Relevant to the KQ	Conclusions	Linked to Effectiveness Data
Goff, 2019[27]	1. A few patients and family members experienced emotional distress in response to the intervention, but others wanted more specific discussions about their prognosis 2. Social workers felt that the intervention promoted interdisciplinary teamwork and put patients in control of the discussions. Nephrologists were satisfied with the intervention but had concerns about feasibility owing to lack of time with patients 3. Outer setting: dialysis disqualifies patients from receiving hospice services unless they have another life-limiting illness in addition to EKSD 4. Inner setting: lack of clinician time was a potential barrier to the intervention; difficulty scheduling advanced care planning sessions because of clinician's busy schedules; felt it was challenging to estimate allotted time due to patient's emotional responses 5. Personal characteristics of clinicians were potential barriers or facilitators to effective implementation of the intervention – several SW became champions for the interventions while others refused to participate 6. Having info about an individual patient's goals and preferences before the intervention was helpful and a reminder sheet of key components to include in the intervention sessions helped with fidelity – SW recommended having hospice materials available during sessions 7. SW felt the intervention would be improved if dialysis workers received ACP training and if training were interprofessional rather than conducted separately 8. Involvement of national dialysis chain leaders as advisors on the study facilitated implementation because of "buy-in."	This study suggests that future efforts to scale-up and implement the SDM-RSC intervention could benefit from additional ACP training for both social workers and nephrologists, including interprofessional training. This study also suggests that some of the barriers identified may be obviated by involving local clinicians, staff, dialysis patients, and their families in decisions about processes for conducting ACP discussions at an early stage of implementation of the intervention. The impact of healthcare policies, such as those that may contribute to a perceived lack of time for ACP discussions in current work flows and challenges to accessing hospice services while on hemodialysis should also be considered if ACP is to be- come a routine practice for healthcare providers and their patients facing the high morbidity and mortality associated with hemodialysis.	Yes – NCT02405312[35]

Author, Year	Themes/Subthemes Identified Relevant to the KQ	Conclusions	Linked to Effectiveness Data
Song, 2017[36]	PROCESS of SPIRIT themes: 1. The SPIRIT intervention was an opportunity for discussion of topics that had previously been avoided (death, life-sustaining treatments, acceptable/unacceptable outcomes, end-of-life preferences). For some, the appreciation for this opportunity changed over time (i.e., they were uncomfortable at first but then they found it helpful), 2. SPIRIT made it easier for patients and surrogates to share their feelings because it started by talking about their experience with the patient's illness rather than starting by talking about death – participants were surprised how comfortable they were talking about it. Impact of SPIRIT themes: 1. SPIRIT was eye-opening – many reported that they didn't realize the life-limiting nature of the patient's illness or that death might be near; many didn't view dialysis as a life-sustaining treatment. Before SPIRIT, people viewed life-sustaining treatment as good or bad, in general, rather than considering circumstances in which life-sustaining treatments may/may not be beneficial. Participants shared understanding of the surrogate's role to make decisions based on patient's (rather than their own) wishes 2. SPIRIT made relationships closer by opening up lines of communication and bringing other family members on board, 3. SPIRIT helped surrogates feel prepared during the time leading up to end-of-life decision-making by helping them realize the possibility of the patient's death and motivating them to seek info they needed from the patient and others, 4. SPIRIT made it easier for surrogates to make decisions and gave them peace of mind with their decisions afterward – a better understanding of their loved one's wishes about end of life was one of the most frequently reported positive outcomes of SPIRIT.	Our data may help explain the beneficial effects of SPIRIT on surrogates, but future trials should include data on control surrogates' perspectives	Yes – Song, 2009[6]

Author, Year	Themes/Subthemes Identified Relevant to the KQ	Conclusions	Linked to Effectiveness Data	Additional Comments
O'Hare, 2016[39]	Four themes emerged regarding barriers to ACP for patients with advanced kidney disease: 1.Medical Care for Patients with Advanced Kidney Disease Is Complex and Fragmented across Settings and Providers and over Time: Providers may be transient and their reach is often limited to a particular phase of the illness trajectory. Lack of clear understanding of how dialysis decisions are made and by which providers. Providers involved in the later stage of the illness wonder why patients are not better prepared for advanced stages of the disease and were struck by how often patients were blindsided when faced with decisions about dialysis. Most ACP decisions occurred in acute setting rather than clinic setting, 2. Lack of a Shared Understanding and Vision of ACP and Its Relationship with Other Aspects of Care: Some providers saw ACP as a series of tasks (ie completing an advanced directive) while as others saw it as an ongoing process that is best supported within an established patient-provider relationship, 3. Unclear Locus of Responsibility and Authority for ACP: Not all providers felt responsible for conducting ACP conversations and felt it was someone else's job or that it wasn't within their scope of practice; vague who is in the "driver's seat" of these conversations, 4. Lack of Active Collaboration and Communication around ACP: Little open communication around ACP; nurses often felt they had a better grasp of patients' circumstances and priorities than nephrologists and expressed nephrologists not always open with patients about what to expect with dialysis and illness trajectory; mismatch between assigned roles and skills to promote ACP.	Complexity and fragmentation of medical care across settings and providers and over time for patients with advanced kidney disease pose a significant challenge to orchestrating the process of ACP among members of this population. Systematic efforts to promote interdisciplinary collaboration among the diverse providers who care for patients with advanced kidney disease will likely be needed to promote effective ACP in this population.	No	

Author, Year	Themes/Subthemes Identified rRlevant to the KQ	Conclusions	Linked to Effectiveness Data	Additional Comments
Bekelman et al. (2011), 6717	Several key themes emerged regarding the content, structure, and timing of palliative care according to patients and caregivers: Content Help us adjust to the limitations of illness and future course of illness adjusting to the limitations and course of HF was the most difficult part of living with it – ask patients how they are doing with HF in the context of their life Asked for help adjusting to and planning for the uncertain course of illness – wanted more detail about the expected course of illness, although this description varied Reduce symptoms, but can you really do anything to help? Fatigue and shortness of breath as most common and distressing symptoms, but were pessimistic of what could be done to alleviate this Structure Who: The provider should be “familiar with my heart condition” Provider should know patient and caregiver and be familiar with their heart condition; some recommended a mental health provider be part of the team What: Involve caregivers and facilitate communication and coordination Caregivers especially asked providers to involve the family and facilitate better communication and coordination How: Use a “team approach” Timing Need for help adjusting to illness at or shortly after the diagnosis of HF and then over time when needed It’s not for everyone – four patients were not interested in the proposed care time as they felt there was nothing else that could be done to help them, they were stable and wanted to keep things the same, or they were afraid a “care team” would compromise another layer of providers without coordination with existing providers; also concerned about additional appointments.	Findings provide guidance for provision of palliative care to HF patients. Early in HF and then as- needed, programs should involve family caregivers, focus on helping patients and families adjust to the limitations and future of illness, and provide symptom relief complementing disease-specific strategies. Training a nurse or social worker to incorporate these services using a collaborative care, team approach is one care model that our study supports. Future research should test the feasibility and effectiveness of integrating such a program into routine HF care.	No	

ACP=advanced care planning; AD=advanced directive; CASA=Collaborative Care to Alleviate Symptoms and Adjust to Illness; CCT=interdisciplinary consultation team; CF=cystic fibrosis; COPD=Chronic obstructive pulmonary disease; EHR=electronic health records; ESKD=end stage kidney disease; HF=heart failure; PACT=Patient Aligned Care Team; PC=palliative care; PCP=primary care provider; POLST=Provider Orders for Life-Sustaining Treatment; QOL=quality of life; SDM-RSC=Shared Decision Making and Renal Supportive Care; SNR=do not resuscitate; SOB=shortness of breath; SPIRIT=Sharing the Patient’s Illness Representations to Increase Trust; SW=social worker.

Table D-42. Risk of bias assessment of randomized controlled trials

Author, Year	Outcome Assessed	Domain 1: Randomization Process	Domain 2: Deviations Intended Interventions (effect of assignment to intervention)	Domain 2: Deviations Intended Interventions (effect of adhering to intervention)	Domain 3: Missing Outcome Data	Domain 4: Measurement of the Outcome	Domain 5: Selection of the Reported Result	Final Assessment
Au, 2012[1]	Patient satisfaction (quality of communication about EOL care-patient satisfaction)	Low risk	Some concerns	Low risk	Low risk	Low risk	Some concerns	Some concerns
Bekelman, 2015[7]	Depression	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Bekelman, 2015[7]	Depression symptom	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Bekelman, 2015[7]	Quality of life	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Bekelman, 2018[8]	Anxiety	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Bekelman, 2018[8]	Depression	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Bekelman, 2018[8]	Dyspnea	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Bekelman, 2018[8]	Fatigue	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Bekelman, 2018[8]	Pain	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Bekelman, 2018[8]	Quality of life	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Curtis, 2018[2]	Advance directive documentation	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Curtis, 2018[2]	Anxiety	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Curtis, 2018[2]	Depression	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Curtis, 2018[2]	Quality of communication	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Some concerns
Dionne-Odom, 2020[9]	Caregiver quality of life	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns

Author, Year	Outcome Assessed	Domain 1: Randomization Process	Domain 2: Deviations Intended Interventions (effect of assignment to intervention)	Domain 2: Deviations Intended Interventions (effect of adhering to intervention)	Domain 3: Missing Outcome Data	Domain 4: Measurement of the Outcome	Domain 5: Selection of the Reported Result	Final Assessment
Dionne-Odom, 2020[9]	Caregiver depression	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Dionne-Odom, 2020[9]	Caregiver anxiety	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Dionne-Odom, 2020[9]	Caregiver burden	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Doorenbos, 2016[3]	Patient satisfaction	Low risk	Low risk	Low risk	Low risk	High risk	Some concerns	High risk
Engelhardt, 2006[10]	Advance directive documentation	Low risk	High risk	High risk	High risk	Some concerns	Some concerns	High risk
Engelhardt, 2006[10]	Satisfaction	Low risk	High risk	High risk	High risk	High risk	High risk	High risk
Goldstein, 2019[13]	Advance directive documentation	Low risk	Some concerns	Low risk	Low risk	Low risk	Low risk	Low risk
Kirchhoff, 2012[4]	Concordance between patients preference and care received	Low risk	High risk	Low risk	Low risk	Low risk	Low risk	High risk
Kirchhoff, 2012[4]	Concordance of care	Low risk	High risk	Low risk	Low risk	Low risk	Low risk	High risk
Kluger, 2020[14]	Quality of life	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Kluger, 2020[14]	Depression symptom	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns

Author, Year	Outcome Assessed	Domain 1: Randomization Process	Domain 2: Deviations Intended Interventions (effect of assignment to intervention)	Domain 2: Deviations Intended Interventions (effect of adhering to intervention)	Domain 3: Missing Outcome Data	Domain 4: Measurement of the Outcome	Domain 5: Selection of the Reported Result	Final Assessment
Kluger, 2020[14]	Anxiety	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Kluger, 2020[14]	Psychological well being	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Kluger, 2020[14]	Caregiver depression	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Kluger, 2020[14]	Caregiver anxiety	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Kluger, 2020[14]	Caregiver psychological well being	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Kluger, 2020[14]	Caregiver burden	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Kluger, 2020[14]	Nonmotor symptom burden	Low risk	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
O'Donnell, 2018[18]	Advance directive documentation	Low risk	Some concerns	High risk	Some concerns	Low risk	Low risk	High risk
O'Donnell, 2018[18]	Anxiety	Low risk	Some concerns	High risk	Some concerns	High risk	Low risk	High risk
O'Donnell, 2018[18]	Depression	Low risk	Some concerns	High risk	Some concerns	High risk	Low risk	High risk
O'Donnell, 2018[18]	Quality of life	Low risk	Some concerns	High risk	Some concerns	High risk	Low risk	High risk
O'Riordan, 2019[19]	Satisfaction	Low risk	Some concerns	High risk	High risk	High risk	Low risk	High risk
O'Riordan, 2019[19]	Quality of life	Low risk	Some concerns	High risk	Low risk	Some concerns	Low risk	High risk

Author, Year	Outcome Assessed	Domain 1: Randomization Process	Domain 2: Deviations Intended Interventions (effect of assignment to intervention)	Domain 2: Deviations Intended Interventions (effect of adhering to intervention)	Domain 3: Missing Outcome Data	Domain 4: Measurement of the Outcome	Domain 5: Selection of the Reported Result	Final Assessment
O'Riordan, 2019[19]	Depression symptom	Low risk	Some concerns	High risk	Low risk	Some concerns	Low risk	High risk
O'Riordan, 2019[19]	Anxiety	Low risk	Some concerns	High risk	Low risk	Some concerns	Low risk	High risk
O'Riordan, 2019[19]	Pain	Low risk	Some concerns	High risk	Low risk	Some concerns	Low risk	High risk
O'Riordan, 2019[19]	Dyspnea	Low risk	Some concerns	High risk	Low risk	Some concerns	Low risk	High risk
O'Riordan, 2019[19]	Advance directive documentation	Low risk	Some concerns	High risk	High risk	Low risk	Low risk	High risk
Perry, 2005[5]	Advance directive documentation	Low risk	Some concerns	High risk	Low risk	Some concerns	Some concerns	High risk
Rogers, 2017[23]	Anxiety	Some concerns	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Rogers, 2017[23]	Depression	Some concerns	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Rogers, 2017[23]	Depression symptom	Some concerns	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Rogers, 2017[23]	Quality of life	Some concerns	Some concerns	Low risk	Low risk	Some concerns	Low risk	Some concerns
Song, 2009[6]	Caregiver satisfaction	Low risk	Some concerns	Some concerns	Low risk	Some concerns	Some concerns	Some concerns
Song, 2009[6]	Patient satisfaction	Low risk	Some concerns	Some concerns	Low risk	Some concerns	Low risk	Some concerns

Table D-43. Risk of bias assessment of non-randomized studies using Cochrane ROBINS-I

Author, Year	Outcome	Domain 1: Confounding	Domain 2: Patient Selection	Domain 3: Classifying Interventions	Domain 4: Deviations from Intended Interventions	Domain 5: Missing Data	Domain 6: Measurement of Outcomes	Domain 7: Selection of Reported Results	Overall Assessment
Lakin, 2017[15-17]	Use and length of hospice care	Serious	Low	Low	Low	Serious	Low	Low	Serious
Feely, 2016[12]	Advance directive	Serious	Low	Low	Low	Moderate	Serious	Low	Serious
Owens, 2012[20]	Depression	Critical	Serious	Low	Moderate	Serious	Serious	Low	Critical
Engelhardt, 2009[11]	Advance directives, satisfaction	Moderate	Low	Low	Low	Moderate	Low	Low	Moderate
Rabow, 2004[21]	HRQOL, satisfaction, utilization	Moderate	Low	Low	Low	Low	Low	Low	Moderate

HRQOL=health related quality of life; ROBINS-I= Risk Of Bias In Non-randomized Studies

Table D-44. Strength of evidence of studies that evaluate the effects of palliative care shared decision-making tools for patients with serious life-threatening chronic illness or conditions in ambulatory settings and their caregivers

Key Outcome	Intervention	Number of Studies (participants)	Study Limitations	Directness	Consistency	Precision	Reporting Bias	Key Findings	Strength of Evidence
Patient satisfaction[1-3, 6]	Shared decision-making tools vs Control	4 RCTs (780 participants)	Moderate	Direct	Consistent	Precise	Undetected	Effective	Low
Caregiver satisfaction[6]	Shared decision-making tools vs Control	1 RCT (54 participants)	Moderate	Direct	N/A	Imprecise	Undetected	Ineffective	Insufficient
Advance directive documentation[2, 3]	Shared decision-making tools vs control	2 RCT (572 participants)	Moderate	Direct	Consistent	Precise	Undetected	Effective	Low
Advance directive documentation[5]	Shared decision-making tools; vs printed materials; and control	1 - 3 arm RCT (203 participants)	High	Indirect	Consistent	Precise	Undetected	Effective	Low
Patient depressive symptoms score[2, 3]	Shared decision-making tools vs control	2 RCTs (342 participants)	Moderate	Direct	N/A	Imprecise	Undetected	Effective	Insufficient

RCT=randomized controlled trial

Table D-45. Strength of evidence of studies that evaluate the effects of palliative care models or multimodal interventions

Key Outcome	Intervention	Number of Studies (participants)	Study Limitations	Directness	Consistency	Precision	Reporting Bias	Key Findings	Strength of Evidence
Patient health-related quality of life	Palliative care models vs usual care or other interventions	6 RCTs (n=897) 2 CTs (n=90+)	RCTs: Moderate CTs: Moderate Overall: Moderate	Direct	Consistent	Precise	Not suspected	Not effective	Moderate
Patient overall symptom burden	Palliative care models vs usual care	2 RCTs (n=419)	Overall: Moderate	Direct	Consistent	Precise	Not suspected	Little to no effect	Low
Patient depressive symptoms score	Palliative care models vs usual care or other interventions	6 RCTs (n=553+) 1 CT (n=90) 2 prospective cohort studies (n=86)	RCTs: Moderate CT/PCs: High Overall: Moderate	Direct	Consistent	Precise	Not reported	Not effective	Moderate
Patient satisfaction	Palliative care models vs usual care	2 RCTs (n=216) 1 CT (n=90)	RCTs: High CT: Moderate Overall: High	Direct	Inconsistent	Precise	Not suspected	Little to no effect	Low
Advance directive documentation	Palliative care models vs usual care	4 RCTs (n=424) 2 CT (n=450) 1 prospective cohort study (n=92)	RCTs: High CT/PCs: High Overall: High	Indirect	Consistent	Precise	Not suspected	Effective	Moderate

CT=controlled trial; n=sample size; PC=prospective cohort; RCT=randomized controlled trial; vs=versus

Table D-46. Joanna Briggs Institute qualitative critical appraisal

Author, Year	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total Score	Overall Quality Rating*
Bekelman, 2011[40]	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	8/10	**High**
Bekelman, 2014[24]	Unclear	Yes	Yes	Yes	Yes	Unclear	Unclear	Yes	Yes	Yes	8/10	**High**
Bekelman, 2016[25]	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	9/10	**High**
Dillon, 2017[26]	Unclear	Yes	Yes	Unclear	Yes	No	No	Yes	Yes	Yes	6/10	**High**
Goff, 2019[27]	Yes	Yes	Unclear	Yes	Yes	Yes	No	Yes	Yes	Yes	8/10	**High**
Hobler, 2018[28]	No	Yes	Yes	Unclear	Unclear	No	Unclear	Yes	Yes	Unclear	4/10	**Low**
Lakin, 2019[29]	Unclear	Yes	Yes	Yes	Yes	Unclear	Yes	Yes	Yes	Yes	8/10	**High**
Long, 2014[30]	No	Yes	Yes	Unclear	Unclear	No	No	Yes	Yes	Unclear	4/10	**Low**
Metzger, 2016[31]	Unclear	Yes	Yes	Yes	Yes	No	Unclear	Yes	Yes	Yes	7/10	**High**
Nowels, 2016[32]	Unclear	Yes	Yes	Yes	Yes	Unclear	No	Yes	Yes	Yes	7/10	**High**
O'Hare, 2016[39]	Unclear	Yes	Unclear	Yes	Unclear	No	Unclear	Yes	Yes	Yes	5/10	**Low**
Paladino, 2019[33]	Unclear	Yes	Unclear	Unclear	Unclear	No	No	Yes	No	Yes	3/10	**Low**
Rabow, 2003[34]	Unclear	Unclear	Unclear	No	No	No	Unclear	Yes	Yes	Unclear	2/10	**Low**

Author, Year	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total Score	Overall Quality Rating*
Scherer, 2018[35]	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	No	Unclear	7/10	**High**
Song, 2016[36]	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	7/10	**High**
Uhler, 2015[37]	Unclear	Yes	Yes	Unclear	Unclear	Unclear	No	Yes	Yes	Unclear	4/10	**Low**
Number of Studies Meeting Criteria*	4/16	15/16	12/16	10/16	10/16	3/16	2/16	16/16	14/16	11/16	--	**Low: 6/16** **High: 10/16**

Q=question.
*Overall Quality: Low, 3-5; High, 6-10.

Table D-47. Percentage of studies meeting criteria using the Joanna Briggs Institute quality assessment

JBI Criteria	% Studies Meeting Criteria
Q1. Is there congruity between the stated philosophical perspective and the research methodology?	25% (4/16)
Q2. Is there congruity between the research methodology and the research question or objectives?	93.8% (15/16)
Q3. Is there congruity between the research methodology and the methods used to collect data?	75% (12/16)
Q4. Is there congruity between the research methodology and the representation and analysis of data?	62.5% (10/16)
Q5. Is their congruity between the research methodology and the interpretation of results?	62.5% (10/16)
Q6. Is there a statement locating the researcher culturally or theoretically?	18.8% (3/16)
Q7. Is the influence of the researcher on the research, and vice-versa, addressed?	12.5% (2/16)
Q8. Are the participants, and their voices, represented?	100% (16/16)
Q9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	87.5% (14/16)
Q10. Do the conclusions drawn from the research report flow from the analysis/ interpretation of the data?	68.8% (11/16)

JBI=Joanna Briggs Institute; Q=question.

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