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

The information in this report is intended to help healthcare decision makers—patients and clinicians, health system leaders, and policymakers, among others—make well-informed decisions and thereby improve the quality of healthcare services. This report is not intended to be a substitute for the application of clinical judgment. Anyone who makes decisions concerning the provision of clinical care should consider this report in the same way as any medical reference and in conjunction with all other pertinent information, i.e., in the context of available resources and circumstances presented by individual patients.

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Suggested citation: [to be included in the final report]
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/reference/purpose.cfm

AHRQ expects that these systematic reviews will be helpful to health plans, providers, purchasers, government programs, and the healthcare system as a whole. Transparency and stakeholder input are essential to the Effective Health Care Program. Please visit the website (www.effectivehealthcare.ahrq.gov) to see draft research questions and reports or to join an e-mail list to learn about new program products and opportunities for input.

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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Technical Expert Panel
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, methodological approaches, and/or conclusions do not necessarily represent the views of individual technical and content experts.

Technical Experts 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 conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential conflicts of interest identified.

The list of Technical Experts who provided input to this report follows:
[to be included in the final report]

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.

The list of Key Informants who provided input to this report follows:
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Peer Reviewers
Prior to publication of the final evidence report, EPCs sought input from independent Peer Reviewers without financial conflicts of interest. However, the conclusions and synthesis of the scientific literature presented in this report do not necessarily represent the views of individual reviewers.
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 non-financial conflicts may be retained. The TOO and the EPC work to balance, manage, or mitigate any potential non-financial conflicts of interest identified.

The list of Peer Reviewers follows:

[to be included in the final report]
Structured Abstract

Objectives. To evaluate effectiveness and implementation of interventions for integrating palliative care into ambulatory care for patients 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 websites (March 2020) and PubMed®, CINAHL, and the Cochrane Central Register of Controlled Trials (November 2019). 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 (HRQOL), patient and caregiver satisfaction, patient overall symptom burden, patient symptoms of depression, and advance directive documentation.

Results. We included 45 web resources, 16 quantitative effectiveness studies and 14 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; they may increase patient satisfaction and advance directive documentation compared with control (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 non-palliative care clinicians are available, we were unable to draw conclusions about implementation and none have been evaluated for effectiveness. Models for integrating palliative care were associated with better depressive symptom scores than usual care and increased advance directive documentation but were not effective for HRQOL (SOE: Moderate for all). Multimodal interventions had little to no effect on advance directive documentation (SOE: Low). We were unable to draw conclusions about overall symptom burden; cost and resource use; 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 have small effects for improving a few outcomes. More research is needed particularly on identification of patients for
these interventions; education for patients, caregivers, and clinicians; and implementation of specific components, characteristics, and factors in models for integrating palliative care.
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**Evidence Summary**

**Main Points**

For integrating palliative care into ambulatory care for patients with serious, life-threatening chronic illness and conditions other than cancer:

- 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.
- Models for integrating palliative care were associated with better depressive symptom scores than usual care and increased advance directive documentation but were not more effective for health-related quality of life.
- Patients and caregivers prefer advance care planning discussions grounded in patient and caregiver experiences and individualized for timing.

**Background and Purpose**

Most care for patients with serious life-threatening chronic illness or conditions, such as 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, either through incorporation of specialty palliative care services or through training of 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?” Since existing recent systematic reviews address integrating palliative care into ambulatory oncology, this review focuses on other serious illness and conditions.

**Methods**

We completed a mixed-methods review focusing on serious chronic illnesses other than cancer; we synthesized and integrated evidence from quantitative and qualitative studies and input from patient/caregiver and clinician/stakeholder Key Informants. We completed searches for studies in November 2019 and will update these during peer review.

**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 45 web resources, 16 quantitative effectiveness studies and 14 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 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 (SOE: Low for both).
- We were unable to draw conclusions about the effect of shared decision-making tools on patient symptoms of depression or caregiver satisfaction because we identified only one small study with moderate risk of bias.
• 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 non-palliative 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 non-palliative 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?
• Models were more effective than usual care for patient symptoms of depression, although differences were likely too small to be clinically meaningful (SOE: Moderate), and for increasing advance directive documentation (SOE: Moderate).
• Models for integrating palliative care were not more effective than usual care for patient health-related quality of life (SOE: Moderate).
• We were unable to draw conclusions about the effectiveness of models for integrating palliative care for overall symptom burden or patient satisfaction (SOE: Insufficient) and no studies addressed caregiver satisfaction.
• Multimodal interventions 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

We identified studies evaluating the effectiveness and implementation of a wide variety of shared decision-making 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. 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 lack of sufficient rigor in qualitative studies; and variations in outcome reporting, particularly for cost and resource use. We could not conduct any meta-analyses given the limitations in outcome reporting. No studies reported 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, characteristics, or factors, 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 were associated with better depressive symptom scores than usual care, although differences were not clinically meaningful, and with increased advance directive documentation. Models for integrating palliative care were not effective for health-related quality of life. More research is particularly needed on the identification of patients for palliative care; educational materials for patients, caregivers, and clinicians and patient outcomes; and specific components, characteristics, and factors in models for integrating palliative care.
Introduction

Background

Most care for patients with serious, life-threatening, chronic illness or conditions occurs in ambulatory settings. Care for these patients can be complex, as patients often experience high symptom burden and other needs and decreased health-related quality of life (HRQOL). Patients may benefit from integration of palliative care into ambulatory care, either through incorporation of specialty palliative care services or through training of 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.” 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. Cancer is also a key area of interest for integrating palliative care but, since existing recent systematic reviews already address integrating palliative care into ambulatory oncology, this review focuses on other illnesses and conditions.

The key decisional dilemma for 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?” A variety of types of interventions can be implemented, separately or together, to 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. 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 specialty palliative care.

Shared decision-making tools. Shared decision-making tools are patient-facing and/or clinician-facing tools to help make decisions for domains such as goals of care communication or symptom management for relevant populations in ambulatory care. A key focus is advance care planning (ACP), or communication about serious illness care goals, defined by the American College of Physicians as a key task in ambulatory care that should occur throughout the course of
a serious illness. Relevant tools may include ACP 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 to educate both palliative care and non-palliative care clinicians that include content about integrating palliative care into ambulatory care.

**Models (care delivery structures) for integrating palliative care and multimodal interventions.** Successful models for integrating palliative care specialist expertise with primary and other ambulatory care address the complexity of care and needs in cases of serious illness and coordination with broader health systems. Key models for integrating palliative care include shared care (where palliative care clinicians work alongside other ambulatory clinicians to meet patients’ palliative care needs) and stepped care (where non-palliative care ambulatory clinicians are trained to meet and support common palliative care needs, with referrals to specialty palliative care when needs are more complex or are not being met). Other types of models for integrating palliative care include supplementary telephone nurse coaching and the integration of social workers into ambulatory care practices. 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 non-palliative 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 non-palliative 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 Methods Appendix for additional details). We report the results of the systematic review in accordance with the Preferred Items for Reporting in Systematic Reviews and Meta-Analyses (PRISMA).7 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,8 and the Joanna Briggs Institute methods for mixed methods systematic reviews.9

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 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 non-palliative 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 non-palliative 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 non-palliative 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 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?

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.

**Figure 1. Analytic framework for integrating palliative care with chronic disease management in ambulatory care**

**Study Selection**

We searched PubMed, CINAHL, and the Cochrane Central Register of Controlled Trials in November 2019 (search is currently being updated for the final report). Two team members independently applied eligibility criteria (Table 1 and Table 2) for these searches. In March 2020, we searched U.S. national websites identified as relevant to the Key Questions and refined with input from AHRQ and Technical Experts, including 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-2 for full list of websites searched). Two reviewers screened website content for eligibility simultaneously based on the Population, Intervention, Comparisons, Outcomes, Type of study, Setting (PICOTS) 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 the Methods Appendix (Appendix A-4).
### 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

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<th>Inclusion</th>
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<tr>
<td><strong>Population</strong></td>
<td><strong>Exclusion</strong></td>
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<td>• 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)</td>
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<tr>
<td>• Clinicians practicing in ambulatory settings (KQ4)</td>
<td>• Studies with only cancer patients</td>
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</tbody>
</table>

| **Interventions**                                                         | **Comparisons**                                                          |
| KQ1: prediction models, tools, or triggers to identify patients for palliative care in ambulatory settings | 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 | 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 | 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 | KQ4: palliative care training or educational materials for ambulatory settings |
| KQ5: models for integrating palliative care or multimodal interventions in 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                  |
| • Studies that report no intervention of interest                         | • Studies that do not report the comparisons of interest                  |
### Table 2. Additional inclusion and exclusion criteria for qualitative, mixed-methods, and process evaluation studies

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comparison</td>
<td>No comparison group needed</td>
<td></td>
</tr>
</tbody>
</table>

**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.¹⁰)
  - 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

**Type of Study**
- Randomized controlled trials
- Non-randomized studies with concurrent controls or historical controls ((controlled trials or prospective cohort studies)

<table>
<thead>
<tr>
<th>Type of Study</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Articles published prior to year 2000</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Non-English publications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Case reports or case series</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Publications with no original data (e.g., editorials, letters, comments, reviews)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Full text not presented or unavailable, abstracts only</td>
</tr>
</tbody>
</table>

**Timing and Setting**
- Any timing
- Ambulatory care settings
- U.S.-based studies

<table>
<thead>
<tr>
<th>Timing and Setting</th>
<th>Inclusion</th>
<th>Exclusion</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Hospital setting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Oncology setting</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Emergency department</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Nursing home and long-term care facilities</td>
</tr>
</tbody>
</table>
## 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).\textsuperscript{11} For non-randomized studies, we used the Cochrane Risk of Bias Assessment Tool for Non-Randomized Studies of Interventions (ROBINS-I tool).\textsuperscript{12} For qualitative and mixed-methods studies, reviewers independently assessed study quality using the Joanna Briggs Institute Checklist\textsuperscript{13, 14} (see Methods Appendix A-12 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 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 planned to conduct meta-analyses when there were sufficient data (i.e., at least three studies) and studies were sufficiently homogenous with respect to key variables (i.e., population characteristics, study duration, intervention, and outcome measures). For outcome measures we determined clinically meaningful differences wherever possible (see Methods Appendix A for additional details).

We completed a mixed-methods review in which we completed separate reviews of the different types of evidence, first, and then integrated these 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 Research adapted for complex interventions and input from the Key Informants (see Methods Appendix A for additional details).\textsuperscript{15}

**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.\textsuperscript{16} We applied evidence grades for the outcomes we classified as critical during protocol development, including patient HRQOL, patient symptom burden, patient symptoms of depression, patient satisfaction, caregiver satisfaction, and advance directive documentation (see the Methods Appendix A-14 for details regarding the domains assessed, the processes for determining the grades, and the definitions of each grade.)
Results

Search Results

We included 45 web resources from the pre-defined key websites, 16 quantitative effectiveness studies (n=2,429), and 14 qualitative implementation studies (n>224); we did not identify any mixed-methods studies (see Appendix B for listing of excluded web resources and studies and Appendix C for listing of included web resources and studies). Details on the results of the searches and summary of key points from Key Informant interviews can be found in Appendix C-10; details on the studies, including characteristics of studies and interventions, risk of bias or quality, and strength of evidence, can be found in Appendix D.

Below, we summarize first what is available [part a) of each KQ], then the review of the quantitative effectiveness studies [part b) of each KQ], and then the review of the qualitative implementation studies [part c) of each KQ]. 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 (KQ1b), patient and caregiver educational resources (KQ2b), or educational resources for clinicians (KQ4b). We also found no studies assessing implementation of prediction models, tools, or triggers (KQ1c) or patient/caregiver educational resources (KQ2c) (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*

<table>
<thead>
<tr>
<th>Intervention type</th>
<th>Web resources</th>
<th>Quantitative effectiveness studies</th>
<th>Qualitative implementation studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prediction models, tools, triggers, guidelines and position statements</td>
<td>14</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Patient/caregiver educational materials and resources</td>
<td>12</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Shared decision-making tools</td>
<td>5</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>Non-palliative care clinician training and educational materials</td>
<td>12</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Models for integrating palliative care</td>
<td>2</td>
<td>9</td>
<td>8</td>
</tr>
<tr>
<td>Multimodal interventions</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>45</td>
<td>16</td>
<td>14</td>
</tr>
</tbody>
</table>

*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.
A. What Is Available?

For each key question below, we describe included web resources from key 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).

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

<table>
<thead>
<tr>
<th>Content Focus</th>
<th>Name of Specific Resource/Intervention</th>
<th>Illness or Condition/Setting</th>
<th>Type of Resource</th>
<th>Organization</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web resources</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient Identification*</td>
<td>LACE Index Scoring Tool for Risk Assessment of Hospital Readmission  <a href="https://www.capc.org/toolkits/patient-identification-and-assessment/">https://www.capc.org/toolkits/patient-identification-and-assessment/</a></td>
<td>Community-based setting</td>
<td>Print</td>
<td>Center to Advance Palliative Care</td>
<td>Free to members</td>
</tr>
<tr>
<td>Patient Identification*</td>
<td>Charlson Comorbidity Index  <a href="https://www.capc.org/toolkits/patient-identification-and-assessment/">https://www.capc.org/toolkits/patient-identification-and-assessment/</a></td>
<td>Community-based setting</td>
<td>Print</td>
<td>Center to Advance Palliative Care</td>
<td>Free to members</td>
</tr>
<tr>
<td>Patient Identification*</td>
<td>Clinical Triggers for PCMH Referral to Palliative Care  <a href="https://www.capc.org/toolkits/patient-identification-and-assessment/">https://www.capc.org/toolkits/patient-identification-and-assessment/</a></td>
<td>Community-based setting</td>
<td>Print</td>
<td>Center to Advance Palliative Care</td>
<td>Free to members</td>
</tr>
<tr>
<td>Patient Identification*</td>
<td>Supportive and Palliative Care Indicators Tool (SPICIT™)  <a href="https://www.capc.org/toolkits/patient-identification-and-assessment/">https://www.capc.org/toolkits/patient-identification-and-assessment/</a></td>
<td>Community-based setting</td>
<td>Print</td>
<td>Center to Advance Palliative Care</td>
<td>Free to members</td>
</tr>
<tr>
<td>Patient Identification*</td>
<td>Walter Prognostic Index  <a href="https://www.capc.org/toolkits/patient-identification-and-assessment/">https://www.capc.org/toolkits/patient-identification-and-assessment/</a></td>
<td>Community-based setting</td>
<td>Print</td>
<td>Center to Advance Palliative Care</td>
<td>Free to members</td>
</tr>
<tr>
<td>Patient Identification*</td>
<td>Comprehensive ICD-10 Codes to Capture Patients with Serious Illness  <a href="https://www.capc.org/toolkits/patient-identification-and-assessment/">https://www.capc.org/toolkits/patient-identification-and-assessment/</a></td>
<td>Community-based setting</td>
<td>Inaccessible</td>
<td>Center to Advance Palliative Care</td>
<td>Free to members</td>
</tr>
<tr>
<td>Patient Identification*</td>
<td>Communicating with Treating Clinicians about the Implications of Frailty  <a href="https://www.capc.org/toolkits/patient-identification-and-assessment/">https://www.capc.org/toolkits/patient-identification-and-assessment/</a></td>
<td>Inaccessible</td>
<td>Inaccessible</td>
<td>Center to Advance Palliative Care</td>
<td>Free to members</td>
</tr>
<tr>
<td>Content Focus</td>
<td>Name of Specific Resource/Intervention</td>
<td>Illness or Condition/Setting</td>
<td>Type of Resource</td>
<td>Organization</td>
<td>Cost</td>
</tr>
<tr>
<td>---------------</td>
<td>-----------------------------------------</td>
<td>------------------------------</td>
<td>------------------</td>
<td>--------------</td>
<td>------</td>
</tr>
<tr>
<td>Patient Identification*</td>
<td>Identifying the Right Patients for Specialty17 <a href="https://www.capc.org/toolkits/patient-identification-and-assessment/">https://www.capc.org/toolkits/patient-identification-and-assessment/</a></td>
<td>Inaccessible</td>
<td>Video</td>
<td>Center to Advance Palliative Care</td>
<td>Free to members</td>
</tr>
<tr>
<td>Patient Identification*</td>
<td>Patient Engagement Guide17 <a href="https://www.capc.org/toolkits/patient-identification-and-assessment/">https://www.capc.org/toolkits/patient-identification-and-assessment/</a></td>
<td>Inaccessible</td>
<td>Inaccessible</td>
<td>Center to Advance Palliative Care</td>
<td>Free to members</td>
</tr>
<tr>
<td>Guidelines</td>
<td>Integrating Palliative Care and Symptom Relief into Primary Health Care19 <a href="https://apps.who.int/iris/bitstream/handle/10665/274559/9789241514477-eng.pdf?ua=1">https://apps.who.int/iris/bitstream/handle/10665/274559/9789241514477-eng.pdf?ua=1</a></td>
<td>General</td>
<td>Print</td>
<td>World Health Organization</td>
<td>Free</td>
</tr>
<tr>
<td>Position Statements</td>
<td>Advance Care Planning32 <a href="https://advancingexpertcare.org/position-statements">https://advancingexpertcare.org/position-statements</a></td>
<td>General</td>
<td>Print</td>
<td>Hospice and Palliative Nurses Association</td>
<td>Free</td>
</tr>
<tr>
<td>Effectiveness studies</td>
<td>Serious Illness Program23, 24</td>
<td>General</td>
<td>Part of intervention</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Effectiveness studies</td>
<td>Implantable cardioverter-defibrillator deactivation</td>
<td>Heart failure</td>
<td>Part of intervention</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

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.

*Patient identification tools included are all those recommended by the Center to Advance Palliative Care in their Patient Identification and Assessment toolkit for Community-Based Providers.

**Multimodal interventions listed with both components (i.e., here and under shared decision-making tools).

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

<table>
<thead>
<tr>
<th>Content Focus</th>
<th>Name of Specific Resource/Intervention</th>
<th>Illness or Condition</th>
<th>Setting</th>
<th>Type of Resource</th>
<th>Organization</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>10 FAQs: Medicare’s Role in End-of-Life Care<a href="https://www.kff.org/medicare/fact-sheet/10-faqs-medicare-role-in-end-of-life-care/">19</a></td>
<td>General</td>
<td>Print</td>
<td>Kaiser Family Foundation</td>
<td>Free</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Getting your Affairs in Order<a href="https://www.nia.nih.gov/health/getting-your-affairs-order">22</a></td>
<td>General</td>
<td>Webpage</td>
<td>National Institute on Aging</td>
<td>Free</td>
<td></td>
</tr>
<tr>
<td>General Information</td>
<td>What Caregivers Should Know About Palliative Care<a href="https://www.aarp.org/caregiving/health/info-2019/palliative-care.html">27</a></td>
<td>General</td>
<td>Webpages</td>
<td>American Association for Retired Persons</td>
<td>Free</td>
<td></td>
</tr>
<tr>
<td>General Information</td>
<td>Palliative Care for People with Respiratory Disease or Critical Illness<a href="https://www.thoracic.org/patients/patient-resources/resources/palliative-care.pdf">31</a></td>
<td>COPD</td>
<td>Print</td>
<td>American Thoracic Society</td>
<td>Free</td>
<td></td>
</tr>
<tr>
<td>General Information</td>
<td>Palliative Care: The Relief You Need When You Have a Serious Illness<a href="https://www.ninr.nih.gov/sites/files/docs/palliative-care-brochure.pdf">32</a></td>
<td>General</td>
<td>Print</td>
<td>National Institute of Nursing Research</td>
<td>Free</td>
<td></td>
</tr>
<tr>
<td>General Information</td>
<td>Cuidados Paliativos: El alivio que necesita cuando tiene una enfermedad grave<a href="https://www.ninr.nih.gov/sites/files/docs/cuidadospaliativos.pdf">13</a></td>
<td>General</td>
<td>Print</td>
<td>National Institute of Nursing Research</td>
<td>Free</td>
<td></td>
</tr>
<tr>
<td>General Information</td>
<td>What is Palliative Care<a href="https://www.ninr.nih.gov/sites/files/docs/palliative-care-brochure.pdf">34</a></td>
<td>General</td>
<td>Webpage</td>
<td>National Institute of Nursing Research</td>
<td>Free</td>
<td></td>
</tr>
<tr>
<td>General Information</td>
<td>What Are Palliative Care and Hospice Care<a href="https://www.nia.nih.gov/health/what-are-palliative-care-and-hospice-care">35</a></td>
<td>General</td>
<td>Webpage</td>
<td>National Institute of Nursing Research</td>
<td>Free</td>
<td></td>
</tr>
<tr>
<td>General Information</td>
<td>Palliative Care Helps Patients with Kidney Disease<a href="https://www.kidney.org/atoz/content/palliative-care-helps-patients-kidney-disease">36</a></td>
<td>ESRD</td>
<td>Webpage</td>
<td>National Kidney Foundation</td>
<td>Free</td>
<td></td>
</tr>
</tbody>
</table>

Effectiveness studies
### Models for integrating palliative care

<table>
<thead>
<tr>
<th>Name of Specific Resource/Intervention</th>
<th>Illness or Condition/Setting</th>
<th>Type of Resource</th>
<th>Organization</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Comprehensive Care Team\textsuperscript{17, 38}</td>
<td>Cancer, COPD, heart failure</td>
<td>Part of intervention</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

### Implementation studies

None identified

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

*Multimodal intervention listed with both components (i.e., here and under models).

---

**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**

<table>
<thead>
<tr>
<th>Content Focus</th>
<th>Name of Specific Resource/Intervention</th>
<th>Illness or Condition/Setting</th>
<th>Type of Resource</th>
<th>Organization</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Web resources</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
| Advance care planning | Planning Today for Tomorrow’s Healthcare: A Guide for People with Chronic Kidney Disease\textsuperscript{19}  
| Advance care planning | The POLST Form\textsuperscript{20}  
[https://cpb-us-w2.wpmucdn.com/blogs.nursing.gwu.edu/dist/a/4/files/2019/05/POLST_Form.pdf](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\textsuperscript{21}  
| Advance care planning | End of Life Planning\textsuperscript{22}  
[https://www.alz.org/help-support/i-have-alz/plan-for-your-future/end_of_life_planning](https://www.alz.org/help-support/i-have-alz/plan-for-your-future/end_of_life_planning) | Dementia | Webpages | Alzheimer’s Association | Free |
| Advance care planning | Planning for Advanced Heart Failure#6264)  
| **Effectiveness studies** | | | | | |
| Advance care planning | Jumpstart-Tips (2 studies)\textsuperscript{23, 24} | lung cancer, COPD, heart failure, cirrhosis, ESRD | Print | N/A | N/A |
**Table 7. What is available: training and educational materials for non-palliative care clinicians on integrating palliative care into ambulatory care for patients with serious life-threatening chronic illness or conditions**

<table>
<thead>
<tr>
<th>Content Focus</th>
<th>Name of Specific Resource/Intervention</th>
<th>Illness or Condition/Setting</th>
<th>Type of Resource</th>
<th>Organization</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Web resources</td>
<td>Educate and Train Professionals[^51] <a href="https://www.alz.org/professionals/public-health/core-areas/educate-train-professionals">https://www.alz.org/professionals/public-health/core-areas/educate-train-professionals</a></td>
<td>Dementia</td>
<td>Webpage</td>
<td>Alzheimer’s Association</td>
<td>Free</td>
</tr>
<tr>
<td></td>
<td>Advanced Care Planning[^52] <a href="https://www.kidneysupportivecare.org/advanced-care-planning/">https://www.kidneysupportivecare.org/advanced-care-planning/</a></td>
<td>ESRD</td>
<td>Webpage</td>
<td>Coalition for Supportive Care of Kidney Patients</td>
<td>Free</td>
</tr>
</tbody>
</table>

[^51]: POLST = Provider Orders for Life-Sustaining Treatment; ESRD = end-stage renal disease; COPD = chronic obstructive pulmonary disease.
[^52]: 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 non-palliative care clinicians caring for patients with serious life-threatening chronic illness or conditions in ambulatory settings?
<table>
<thead>
<tr>
<th>Content Focus</th>
<th>Name of Specific Resource/Intervention</th>
<th>Illness or Condition/Setting</th>
<th>Type of Resource</th>
<th>Organization</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance Care Planning</td>
<td>Improving Advance Care Planning: Research Results from the “Conversation Starters” Focus Groups and “Conversation Stopper” Physician Survey[^54] <a href="https://www.johnahartford.org/dissemination-center/view/advance-care-planning-poll">https://www.johnahartford.org/dissemination-center/view/advance-care-planning-poll</a></td>
<td>General</td>
<td>Webpage</td>
<td>Hartford Foundation</td>
<td>Free</td>
</tr>
<tr>
<td>Advance Care Planning</td>
<td>POLST Paradigm[^57] <a href="https://www.pewtrusts.org/-/media/assets/2016/07/documentingendoflifewisheswithphysicianordersforlifesustainingtreatmentpolstpardigm.pdf">https://www.pewtrusts.org/-/media/assets/2016/07/documentingendoflifewisheswithphysicianordersforlifesustainingtreatmentpolstpardigm.pdf</a></td>
<td>General</td>
<td>Print</td>
<td>Pew Charitable Trusts</td>
<td>Free</td>
</tr>
<tr>
<td>General Information</td>
<td>Defining Hope[^58] <a href="https://hope.film/study-guide-videos/">https://hope.film/study-guide-videos/</a></td>
<td>General</td>
<td>14 videos, print</td>
<td>American Nurses Association/Foundation</td>
<td>Free</td>
</tr>
<tr>
<td>General Information</td>
<td>Downloadable Tools for Making the Case[^59] <a href="https://www.capc.org/tools-for-making-the-case/downloadable-tools/">https://www.capc.org/tools-for-making-the-case/downloadable-tools/</a></td>
<td>General</td>
<td>Webpages, toolkit</td>
<td>Center to Advance Palliative Care</td>
<td>Free to members</td>
</tr>
<tr>
<td>General Information</td>
<td>Supporting the Caregivers of People Living with Dementia[^60] <a href="https://www.capc.org/training/best-practices-in-dementia-care-and-caregiver-support/supporting-caregivers-people-living-dementia/">https://www.capc.org/training/best-practices-in-dementia-care-and-caregiver-support/supporting-caregivers-people-living-dementia/</a></td>
<td>Dementia</td>
<td>Toolkit with 13 printable resources</td>
<td>Center to Advance Palliative Care</td>
<td>Free to members</td>
</tr>
</tbody>
</table>
## 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 *

<table>
<thead>
<tr>
<th>Content Focus</th>
<th>Name of Specific Resource/Intervention</th>
<th>Illness or Condition/Setting</th>
<th>Type of Resource</th>
<th>Organization</th>
<th>Cost</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Web resources</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Models</td>
<td>Primary Care First Model Options62</td>
<td>Primary care</td>
<td>Webpage</td>
<td>Centers for Medicare &amp; Medicaid Services</td>
<td>Free</td>
</tr>
<tr>
<td>Models</td>
<td>Models and Strategies to Integrate Palliative Care Principles into Care for People with Serious Illness: Proceedings of a Workshop63</td>
<td>Broad range of patient populations, clinical settings</td>
<td>Print</td>
<td>National Academies of Sciences, Engineering, and Medicine</td>
<td>Free</td>
</tr>
<tr>
<td><strong>Effectiveness studies</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Models</td>
<td>Social-worker led palliative care64</td>
<td>Heart failure</td>
<td>Intervention</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Models</td>
<td>Collaborative Care to Alleviate Symptom and Adjust to Illness65</td>
<td>Heart failure</td>
<td>Intervention</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Models</td>
<td>Patient-Centered Disease Management66</td>
<td>Heart failure</td>
<td>Intervention</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Models</td>
<td>Integrated palliative care67</td>
<td>ESRD</td>
<td>Intervention</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Models</td>
<td>Primary Palliative Care Clinic68</td>
<td>Primary care</td>
<td>Intervention</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Models</td>
<td>Advanced Illness Coordinated Care Program (2 studies)69,70</td>
<td>COPD, heart failure, end-stage pulmonary disease, ESRD, cancer</td>
<td>Intervention</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Models</td>
<td>Comprehensive Care Team37, 38</td>
<td>Cancer, COPD, heart failure</td>
<td>Intervention</td>
<td>N/A</td>
<td>N/A</td>
</tr>
<tr>
<td>Models</td>
<td>Control with Palliative Care in Heart Failure71</td>
<td>Heart failure</td>
<td>Intervention</td>
<td>N/A</td>
<td>N/A</td>
</tr>
</tbody>
</table>

**POLST** = Provider Orders for Life-Sustaining Treatment; **ESRD** = end-stage renal disease.
| Models | Collaborative Care to Alleviate Symptoms and Adjust to Illness<sup>72</sup> | Heart failure, hypertension, COPD | Intervention | N/A | N/A |
| Models | Serious Illness Care Program<sup>73</sup> | Primary care | Intervention | N/A | N/A |
| Models | Palliative care<sup>54</sup> | COPD | Intervention | N/A | N/A |
| Models | Comprehensive Care Team<sup>75</sup> | COPD, heart failure, cancer | Intervention | N/A | N/A |
| Models | Communication intervention<sup>76</sup> | ESRD | Intervention | N/A | N/A |

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

*Note that multimodal interventions are listed under the specific components above; if models included other components, these studies are also listed in those tables.*
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
- Palliative care shared decision-making tools may improve patient satisfaction with communication (SOE: Low).
- Palliative care shared decision-making tools may increase advance directive documentation (SOE: Low).
- We could not draw conclusions about the effect of shared decision-making tools on caregiver satisfaction or patient symptoms of depression, and no studies addressed other critical outcomes.

Five RCTs assessed the effectiveness of palliative care shared decision-making tools for patients and caregivers in ambulatory settings.43-47 These five studies included 1,487 patients (overall mean age ranged from 19 to 83 years) and 58 caregivers (overall mean age was 48 years). Two studies were conducted with ESRD patients on dialysis; one with ESRD patients on dialysis or with heart failure; one with COPD patients; and one with multiple serious illnesses, including lung cancer, chronic obstructive lung disease, heart failure, cirrhosis, and ESRD. (Table 9, see Results Appendix D for full study characteristics).

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

<table>
<thead>
<tr>
<th>Author, year</th>
<th>Study characteristics</th>
<th>Intervention description</th>
<th>Followup duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Author, year</td>
<td>Study characteristics</td>
<td>Intervention description</td>
<td>Followup duration</td>
</tr>
<tr>
<td>-------------</td>
<td>-----------------------</td>
<td>-------------------------</td>
<td>------------------</td>
</tr>
</tbody>
</table>
| Curtis, et al., 2018<sup>43</sup> | 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 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<sup>44</sup> | 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<sup>45</sup> | 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, offering 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) |
| Perry, et al., 2005<sup>46</sup> | n=203 Multi-setting, 3-arm RCT, academic, 21 dialysis centers, Patients with ESRD 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 |
<table>
<thead>
<tr>
<th>Author, year</th>
<th>Study characteristics</th>
<th>Intervention description</th>
<th>Followup duration</th>
</tr>
</thead>
<tbody>
<tr>
<td>Song, et al., 2009</td>
<td>n=116 Multi-Setting, RCT, pre-/post-test, nephrology, community dialysis clinics</td>
<td>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. <strong>Outcomes:</strong> Patient and caregiver satisfaction</td>
<td>3 months</td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Number of studies</th>
<th>Satisfaction</th>
<th>Symptoms of depression</th>
<th>Symptoms of anxiety</th>
<th>Concordance between patient preferences and care received</th>
<th>Advance Directive documentation</th>
<th>Dropouts related to the intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>Patient - 3</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Caregiver - 1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Comparison</th>
<th>Number of Studies (N)</th>
<th>Findings</th>
<th>Strength of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient and caregiver-centered outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient satisfaction(^{41,44,47})</td>
<td>Shared decision-making tools vs. control</td>
<td>3 RCTs (1,029 participants)</td>
<td>Shared decision-making tools may improve patient satisfaction more than control.</td>
<td>Low</td>
</tr>
<tr>
<td>Caregiver satisfaction(^37)</td>
<td>Shared decision-making tools vs. control</td>
<td>1 RCT (116 participants)</td>
<td>We were unable to draw conclusions.</td>
<td>Insufficient</td>
</tr>
<tr>
<td>Patient symptoms of depression(^43)</td>
<td>Shared decision-making tools vs. control</td>
<td>1 RCT (537 participants)</td>
<td>We were unable to draw conclusions.</td>
<td>Insufficient</td>
</tr>
<tr>
<td>Patient symptoms of anxiety(^43)</td>
<td>Shared decision-making tools vs. control</td>
<td>1 RCT (537 participants)</td>
<td>We were unable to draw conclusions.</td>
<td>Not graded</td>
</tr>
<tr>
<td>Concordance between patient preferences and care received(^43,45)</td>
<td>Shared decision-making tools vs. control</td>
<td>2 RCTs (850 participants)</td>
<td>Shared decision-making tools may improve concordance between patient preferences and care received, but it is not clear if the reported differences are meaningful.</td>
<td>Not graded</td>
</tr>
</tbody>
</table>

Healthcare Utilization
<table>
<thead>
<tr>
<th>Outcome</th>
<th>Comparison</th>
<th>Number of Studies (N)</th>
<th>Findings</th>
<th>Strength of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Advance directives documentation(^{43, 46})</td>
<td>Shared decision-making tools vs. printed materials</td>
<td>1 RCT (203 participants) (3 arms)</td>
<td>Shared decision-making tools may be more effective than printed materials or control for increasing advance directives documentation.</td>
<td>Low</td>
</tr>
<tr>
<td></td>
<td>Shared decision-making tools vs. control</td>
<td>2 RCTs (740 participants)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Adverse effects</td>
<td>Dropouts related to the intervention(^{44})</td>
<td>1 RCT (376 participants)</td>
<td>We were unable to draw conclusions.</td>
<td>Not graded</td>
</tr>
<tr>
<td></td>
<td>Shared decision-making tools vs. control</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^{RCT} = \text{randomized control trial}\)

### Patient- and Caregiver-centered Outcomes

#### Patient Satisfaction

Three RCTs of shared decision-making tools evaluated patient satisfaction, measured as quality of patient-clinician communication\(^{43, 44, 47}\). 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\(^{44}\) or mixed serious illness populations\(^{43}\). One study used a trained nurse interventionist to enhance communication between ESRD patients and caregivers about end-of-life care\(^{47}\). All studies used versions of the Quality of Communication questionnaire; two used a version focusing on end-of-life care\(^{43, 47}\).

Of the two feedback trials to enhance communication in goals-of-care conversations, one study (n=376) reported a between group improvement in the intervention group compared with usual care of 5.7 points on a 100-point scale (CI not reported; p=0.03; Cohen effect size, 0.21).\(^{44}\) Final results for the other trial (n=536) 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).\(^{43}\) The 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 (11.30 ± 1.41) and control group (7.52 ± 3.66, on a 4- to 12-point scale, no statistics reported) (n=116).\(^{47}\) We were unable to conduct a meta-analysis owing to incomplete reporting of results and heterogeneity of interventions. We could not determine if any differences between groups were clinically meaningful. Shared decision-making tools may improve patient satisfaction, but the improvement may or may not be clinically meaningful and our confidence is limited by a moderate risk of bias in the studies (SOE: Low).

#### Caregiver Satisfaction

The RCT (n=58) 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 Quality of Communication questionnaire\(^{47}\). The study did not report baseline results but reported results at the end of the study for the intervention group (11.58 ± 0.72) and control group (10.22 ± 2.49 on a 4- to 12-point scale). 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
One RCT 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-8 scale. The study reported results only at the end of the study: 4.88 (95% CI, 4.23 to 5.54) in the control group compared with 5.92 (95% CI, 5.19 to 6.66) in the intervention group (p=0.54). We could not draw a conclusion about the effect of shared decision-making tools on patient symptoms of depression, owing to lack of precision and moderate risk of bias (SOE: Insufficient).

Symptoms of Anxiety
One RCT 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. The study reported followup results only of 3.00 (95% CI, 2.44 to 3.57) in the control group compared with 3.26 (95% CI, 2.64 to 3.89) in the intervention group (p=0.94). We could not draw a conclusion about the effect of shared decision-making tools on patient anxiety owing to lack of precision and moderate risk of bias (SOE: Insufficient).

Concordance Between Patient Preferences and Care Received
Two RCTs examined concordance between patient preferences and care received. One study evaluated an intervention to enhance communication in goals-of-care conversations between clinicians and patients, and one study used a 1- to 1.5-hour interview intervention conducted by a trained facilitator. 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). 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). 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
Two RCTs evaluated the impact of interventions on advance directive or goals-of-care documentation (total n=740). One study evaluated an intervention to enhance communication in goals-of-care conversations between clinicians and patients. In this study, documentation of goals-of-care conversations occurred in 62 percent of in 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. 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 control group (p<0.05) and 10 percent (8/81) in the control group (OR 0.25, p<0.01). In the two studies, the increases in documentation were consistent and clinically meaningful. Shared decision-making tools were effective for increasing advance directives documentation (SOE: Low).

Adverse Effects
Dropouts related to the intervention

Only one RCT evaluated dropouts related to the intervention. This trial evaluated an intervention to enhance communication in goals-of-care conversations between clinicians and patients. There was no difference in dropouts between the intervention and control group (22% vs. 15%, p=0.60).

Key Question 4b. What is the effectiveness of 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?

We identified no studies for this key question.
Key Question 5b: What is the effectiveness of models or 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 care were more effective than usual care for depressive symptom scores, although differences were likely too small to be clinically meaningful (SOE: Moderate), and for increasing advance directive documentation (SOE: Moderate).
- Models for integrating palliative care were not shown to be more effective than usual care for patient HRQOL (SOE: Moderate).
- We were unable to draw conclusions about the effectiveness of models for integrating palliative care for patient satisfaction or overall symptom burden (SOE: Insufficient), and no studies addressed caregiver satisfaction.
- We were unable to draw conclusions about the effectiveness of multimodal interventions for advance directive documentation (SOE: Insufficient), and no studies addressed the effect of multimodal interventions for other critical (graded) outcomes.

Description of Included Studies

We identified 13 articles describing 11 studies assessing the effectiveness of models for integrating palliative care or multimodal interventions for integrating palliative care in ambulatory settings. These 11 studies included 2,429 patients and 143 caregivers. Six studies were randomized trials 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 nine trials assessing models for integrating palliative care, one also included clinician training and education and one also included patient/caregiver education. Four were shared care models (where non-palliative care and palliative care clinicians worked together), three were integrating care coordinators or social workers into care, one combined both these model types, and one used a consultative model (where palliative care consultants saw patients). Followup ranged from 2 weeks to 2 years. Five studies were multicenter [Table 14, see Results Appendix D (evidence tables) for full study characteristics].

<table>
<thead>
<tr>
<th>Author, year</th>
<th>Study characteristics</th>
<th>Intervention description</th>
<th>Followup duration</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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<tr>
<td>Author, year</td>
<td>Study characteristics</td>
<td>Intervention description</td>
<td>Followup duration</td>
</tr>
<tr>
<td>-----------------</td>
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</tr>
<tr>
<td>O'Donnell, 2018</td>
<td>n=50</td>
<td>• Control: Usual care on advanced care planning and health-related quality of life&lt;br&gt;• 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.&lt;br&gt;• Model type: Integrating social workers into practice</td>
<td>6 months</td>
</tr>
<tr>
<td></td>
<td>RCT, single-center, academic</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patients with heart failure who had recent hospitalization and are at high risk for poor prognosis</td>
<td></td>
<td></td>
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<tr>
<td></td>
<td>Private foundation funding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bekelman, 2018</td>
<td>n=314</td>
<td>• 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.&lt;br&gt;• 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 follow-up visits (8 hours).&lt;br&gt;• Model type: Shared care</td>
<td>6 months</td>
</tr>
<tr>
<td></td>
<td>RCT, multi-center, academic and Veterans Affairs health systems</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Primary site not reported, patients with heart failure and reduced health status</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Government funding</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Author, year</td>
<td>Study characteristics</td>
<td>Intervention description</td>
<td>Followup duration</td>
</tr>
<tr>
<td>--------------</td>
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<td>------------------</td>
</tr>
</tbody>
</table>
| Bekelman, 2015<sup>56</sup> | 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 enrolment 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: Shared care and integrating care coordinators into practice | 12 months |
| Feely, 2016<sup>67</sup> | 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 |
| Owens, 2013<sup>51</sup> | 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 |
| Engelhardt, 2006<sup>59</sup> | n=186 patients and n=143 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: Integrating care coordinators into practice | 6 months |
<table>
<thead>
<tr>
<th>Author, year</th>
<th>Study characteristics</th>
<th>Intervention description</th>
<th>Followup duration</th>
</tr>
</thead>
</table>
| Engelhardt, 2009<sup>70</sup> | n=403  
- Controlled trial, multi-center, integrated managed care  
- Kaiser Permanente health system, patients with advanced stages of cancer, congestive heart failure, end-stage pulmonary disease, and end-stage renal disease and their caregivers  
- Non-profit 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: Integrating care coordinators into practice | Varied, 4 to 9 months |
| Rabow, 2004<sup>31, 38</sup> | 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: Shared care plus patient/caregiver education | 12 months |
| Rogers, 2017<sup>71</sup> | 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: Control with 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 |

COPD = chronic obstructive pulmonary disease; CHF = congestive heart failure; CCT = comprehensive care team; AICCP = advanced illness coordinated care program; PCDM = patient-centered disease management; CASA = collaborative care to alleviate symptoms and adjust to illness; RCT = randomized controlled trial.
Table 13. Characteristics of effectiveness studies assessing multimodal interventions

<table>
<thead>
<tr>
<th>Author, year</th>
<th>Study characteristics</th>
<th>Intervention description</th>
<th>Followup duration</th>
</tr>
</thead>
</table>
| Lakin, 2017\textsuperscript{23, 24} | 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\textsuperscript{17} | n=525  
• 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 |

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

<table>
<thead>
<tr>
<th>Number of Studies</th>
<th>Satisfaction</th>
<th>HRQOL</th>
<th>Overall symptom burden</th>
<th>Symptoms of depression</th>
<th>Symptoms of anxiety</th>
<th>Psychological well-being</th>
<th>Pain</th>
<th>Dysspnea</th>
<th>Fatigue</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multimodal Interventions</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Number of Studies</td>
<td>Satisfaction</td>
<td>HRQOL</td>
<td>Overall symptom burden</td>
<td>Symptoms of depression</td>
<td>Symptoms of anxiety</td>
<td>Psychological well-being</td>
<td>Pain</td>
<td>Dyspnea</td>
<td>Fatigue</td>
</tr>
<tr>
<td>-------------------</td>
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<td>------------------------</td>
<td>-------------------</td>
<td>-------------------------</td>
<td>------</td>
<td>---------</td>
<td>---------</td>
</tr>
<tr>
<td>Models for integrating palliative care</td>
<td>9</td>
<td>2</td>
<td>6</td>
<td>1</td>
<td>7</td>
<td>6</td>
<td>2</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

HRQOL = health-related quality of life.

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

<table>
<thead>
<tr>
<th>Number of Studies</th>
<th>Concordance</th>
<th>Use and length of hospice care</th>
<th>Hospitalizations</th>
<th>AD documentation</th>
<th>Cost and resource use</th>
<th>Dropouts related to the intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Multimodal Interventions</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Models for integrating palliative care</td>
<td>9</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>5</td>
<td>4</td>
</tr>
</tbody>
</table>

AD = advance directive.
<table>
<thead>
<tr>
<th>Outcome</th>
<th>Comparison</th>
<th>Number of Studies (N)</th>
<th>Findings</th>
<th>Strength of Evidence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient and caregiver-centered outcomes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Patient satisfaction</td>
<td>Models for integrating palliative care vs. usual care</td>
<td>1 RCT (n=186) 1 CT (n=90)</td>
<td>Due to the small and inconsistent results we were unable to draw a conclusion about the effect of models on patient satisfaction.</td>
<td>Insufficient</td>
</tr>
<tr>
<td>Patient health-related quality of life</td>
<td>Models for integrating palliative care vs. usual care</td>
<td>4 RCT (n=906) 2 CT (n=493)</td>
<td>Results were consistently not statistically or clinically different between groups. Models were not more effective than usual care for HRQOL.</td>
<td>Moderate</td>
</tr>
<tr>
<td>Overall symptom burden</td>
<td>Models for integrating palliative care vs usual care</td>
<td>1 RCT (n=314)</td>
<td>Due to only one study with inclusive results, we were unable to draw conclusions about the effect of models on overall symptom burden.</td>
<td>Insufficient</td>
</tr>
<tr>
<td>Patient symptoms of depression</td>
<td>Models for integrating palliative care vs. usual care</td>
<td>4 RCTs (n=906) 1 CT (n=90) 2 prospective cohort studies (n=92)</td>
<td>There were statistically significant between-group differences for depression, but differences were too small to be clinically meaningful. Models were more effective than usual care for depression, although differences are likely too small to be clinically meaningful.</td>
<td>Moderate</td>
</tr>
<tr>
<td>Patient symptoms of anxiety</td>
<td>Models for integrating palliative care vs. usual care</td>
<td>3 RCT (n=514) 1 CT (n=90) 2 prospective cohort studies (n=141)</td>
<td>No statistically or clinically significant between-group differences. Models were not more effective than usual care for anxiety.</td>
<td>Not graded</td>
</tr>
<tr>
<td>Patient psychological well-being</td>
<td>Models for integrating palliative care vs. usual care</td>
<td>2 CT (n=493)</td>
<td>There were differences, but not all were clinically meaningful.</td>
<td>Not graded</td>
</tr>
<tr>
<td>Pain</td>
<td>Models for integrating palliative care vs. usual care</td>
<td>1 RCT (n=314) 1 CT (n=90) 2 prospective cohort studies (n=141)</td>
<td>None of the differences were clinically meaningful suggesting that models were not more effective than usual care for pain.</td>
<td>Not graded</td>
</tr>
<tr>
<td>Outcome</td>
<td>Comparison</td>
<td>Number of Studies (N)</td>
<td>Findings</td>
<td>Strength of Evidence</td>
</tr>
<tr>
<td>---------</td>
<td>------------</td>
<td>----------------------</td>
<td>----------</td>
<td>----------------------</td>
</tr>
<tr>
<td>Dyspnea</td>
<td>Models for integrating palliative care vs. usual care</td>
<td>1 RCT (n=314) 1 CT (n=90) 2 prospective cohort studies (n=141)</td>
<td>Primarily based on the larger RCT results, models may not be more effective than usual care for dyspnea.</td>
<td>Not graded</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Models for integrating palliative care vs. usual care</td>
<td>1 RCT (n=314) 2 prospective cohort studies (n=141)</td>
<td>Primarily based on the larger RCT results, models may not be more effective than usual care for fatigue.</td>
<td>Not graded</td>
</tr>
<tr>
<td>Concordance between patient preferences and care received</td>
<td>Models for integrating palliative care vs. usual care</td>
<td>1 RCT (n=50)</td>
<td>We were unable to draw conclusions.</td>
<td>Not graded</td>
</tr>
<tr>
<td>Healthcare Utilization</td>
<td>Use and length of hospice care</td>
<td>Multimodal interventions vs. usual care</td>
<td>1 CT (n=178)</td>
<td>We were unable to draw conclusions.</td>
</tr>
<tr>
<td>Hospitalizations</td>
<td>Multimodal interventions vs. usual care</td>
<td>1 RCT (n=525) 2 RCT (n=706) 2 CT (n=622)</td>
<td>Multimodal: Results of one large RCT suggest that use of multimodal intervention has little to no effect on hospitalizations. Models: Models were not more effective than usual care for hospitalizations.</td>
<td>Not graded</td>
</tr>
<tr>
<td>Advance directive documentation</td>
<td>Multimodal interventions vs. usual care</td>
<td>1 RCT (n=525) 2 RCTs (n=325) 2 CT (n=532) 1 prospective cohort studies (n=92)</td>
<td>Multimodal: Based on a large low risk of bias study, multimodal interventions have little to no effect on advance directive documentation. Models: Models are more effective vs. usual care.</td>
<td>Low Moderate</td>
</tr>
<tr>
<td>Cost and resource use.</td>
<td>Models for integrating palliative care vs. usual care</td>
<td>1 RCT (n=186) 2 CT (n=493) 1 prospective cohort study (n=49)</td>
<td>Studies varied widely in reporting and results so we were unable to draw conclusions.</td>
<td>Not graded</td>
</tr>
</tbody>
</table>
### Patient- or Caregiver-reported Outcomes

#### Satisfaction

**Models for integrating palliative care**

No studies of models for integrating palliative care evaluated caregiver satisfaction. One RCT and one CT, reported in three articles, assessed the effect of models for integrating palliative care on patient satisfaction.\(^{37, 38, 69}\) Both studies evaluated patient-caregiver training/education combined with an integrated model compared with control, one evaluating over a period of 12 months and the other over a period of 6 months.

In the 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).\(^{69}\) It is not clear whether this is a meaningful difference and the CT reported conflicting results. 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).\(^{37, 38}\) We were unable to draw a conclusion about the effect of models for integrating palliative care on patient satisfaction owing to the small and inconsistent results (SOE: Insufficient).

**Multimodal interventions**

No studies evaluating multimodal interventions assessed patient or caregiver satisfaction.

#### Health-related quality of life

**Models for integrating palliative care**

Four RCTs and two CTs, reported in seven articles, assessed the effect of models for integrating palliative care on HRQOL.\(^{37, 38, 64-66, 70, 71}\)

The four 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 RCT also used the Functional Assessment of Chronic Illness Therapy – Palliative Care scale (FACIT-PAL). We were unable to conduct a meta-analysis, as two RCTs were missing either followup data or variability measurements.

We were able to calculate a mean between-group difference of the KCCQ for two trials, each of which assessed the impact of an integrated model on heart failure patients at 6 months. The first RCT assessed the effect of integrating social workers into care and had a relatively smaller sample size (n=50). The calculated mean between-group difference was -2.4 (95% CI, -30.2 to 25.4). The second RCT evaluated the effect of a shared care model on a larger sample (n=150)
and had a calculated mean between-group difference of 4.1 (95% CI, -11.4 to 19.6). Neither result was clinically meaningful. 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 assessed the effect of a shared care model on heart failure patients in a veteran population, one over a period of 6 months and the other over a period of 12 months. The first RCT combined the shared care model with clinician training (n=314) and reported a difference of 2.6 (95% CI, -1.3 to 6.6) between groups at 6 months (p=0.19). The second RCT combined the shared care model with integrating care coordinators (n=342) and reported that, at 1 year, scores had increased by 13.5 for both the control and intervention groups (p=0.97). Neither result was clinically meaningful.

The two CTs assessed wider populations including cancer, heart failure and COPD patients, one over a period of 4 to 9 months and the other over a period of 12 months. One CT evaluated the impact of a shared care model combined with patient/caregiver education on HRQOL with the Multidimensional Quality of Life Scale – Cancer Version (0- to 100-point scale). At 12 months, the control group reported a HRQOL total mean score of 67.7 compared with the intervention group mean score of 69.3 (p=0.43). No variability was reported, so we were unable to calculate a mean between-group difference. The second CT assessed the impact of integration of care coordinators on 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 were consistently not statistically or clinically meaningful. Models for integrating palliative care did not improve HRQOL (SOE: Moderate).

**Multimodal interventions**

No studies evaluating multimodal interventions assessed HRQOL.

**Overall symptom burden**

**Models for integrating palliative care**

One RCT (n=314) assessed the effect of models for integrating palliative care on overall symptom burden. The study assessed the effect of a shared care model on heart failure patients over 6 months. Symptom burden was described using the General Symptom Distress Scale (GSDS). At 6 months, the reported mean between group difference was 0.1 (95% CI, -0.5 to 0.7), p = 0.8. We were unable to draw conclusions about the effect of models for integrating palliative care on overall symptom burden (SOE: Insufficient), as only one study had inconclusive results.

**Multimodal interventions**

No studies evaluating multimodal interventions assessed overall symptom burden.

**Symptoms of depression**

**Models for integrating palliative care**

Four RCTs, one CT and two prospective cohort studies, reported in eight articles, assessed the effect of models for integrating palliative care on depression. Depression was assessed using a wide variety of scales.
Two RCTs assessed depression with the Patient Health Questionnaire-9 (PHQ9) (0- to 27-point range). Both assessed the effect of a shared care model on heart failure patients in a veteran population, one over a period of 6 months and one over a period of 12 months. The first RCT combined the shared care model with clinician training (n=314) and reported a difference of -1.4 (95% CI, -2.6 to -0.2) between groups (p=0.02).65 The other RCT combined the shared care model with integrating care coordinators (n=342) and reported a difference of 2.1 (95% CI, 0.43 to 3.78) between groups (p=0.01).66 Although these results were statistically significantly different, neither was clinically meaningful.

The other two RCTs also compared the effect of models for integrating palliative care in heart failure populations over a period of 6 months. One RCT assessed the impact of integrating social workers into practice (n=50) on depression with the Patient Health Questionnaire-8 (PHQ-8) (0- to 24-point range) with a calculated mean between-group difference of -0.6 (95% CI, -7.2 to 6) at 6 months (p=0.52).64 The other RCT assessed the impact of a shared care model on depression (n=150) using the Hospital Anxiety and Depression Scale (HADS) (0- to 21-point range) and reported a difference of -1.94 (95% CI, 3.57 to -0.31) between groups (p=0.02) that was also clinically significant.71

The two prospective cohort studies assessed depression with the Edmonton Symptom Assessment Scale (ESAS) (a 10-point scale). One cohort assessed the impact of a consultative care intervention on depression in patients on hemodialysis (n=92) with a reported change from a mean of 0.96 +/- 1.99 at baseline to 0.87 +/- 2.29 (p=0.7) at 6 months.67 The other cohort assessed the impact of a shared care model on a wider patient population (n=49) over a time period ranging from 2 weeks to 9 months. Depression scores in this cohort changed from a mean (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 combined with patient/caregiver education on depression with the Center for Epidemiological Studies Depression Scale. At 12 months, the control group reported a score of 15.3 compared with 12.4 in the intervention arm (p=0.28).37, 38

We were unable to conduct a meta-analysis owing to missing baseline and/or variability data. Models for integrating palliative care are associated with better depression scores compared with usual care, but the differences are likely too small to be clinically meaningful (SOE: Moderate).

Multimodal interventions

No studies evaluating multimodal interventions assessed symptoms of depression.

Anxiety

Models for integrating palliative care

Three RCTs, one CT and two prospective cohort studies assessed the effect of models for integrating palliative care on anxiety.37, 38, 64, 65, 67, 68, 71

All three RCTs assessed the impact of models for integrating palliative care on heart failure patients over a period of 6 months. Two of the RCTs assessed anxiety with the Generalized Anxiety Disorder-7 item scale (GAD-7). We were able to calculate a mean between-group difference for one trial. That RCT evaluated the impact of integrating social workers into practice on anxiety (n=50) and had a calculated mean between-group difference of -5.6 (95% CI, -11.7 to 0.52).64 The second RCT assessed the impact of a shared care model combined with
clinician training/education (n=314) and reported a difference of -0.9 (95% CI, -2 to 0.13) between groups at 6 months (p=0.09).65 The third RCT assessed the impact of a shared care model (n=150) 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).71

One prospective cohort study evaluated a consultative model on a hemodialysis unit over a period of 6 months (n=92).67 The other evaluated the effect of a shared care model on a wider patient population (n=49) over a time period ranging from 2 weeks to 9 months.68 Both prospective cohort studies assessed anxiety with the Edmonton Symptom Assessment Scale (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).67 In the other cohort, anxiety changed from a mean (SD) of 1.65 (2.47) to 1.94 (2.5) (no statistics reported).68

The CT evaluated patient-caregiver training/education combined with a shared care model in patients with COPD, CHF and cancer over a period of 12 months (n=90).37, 38 Using the Profile of Mood States, the control group reported a score of 5.9 compared with 5.3 in the intervention arm (p=0.68).37, 38

We were unable to conduct a meta-analysis owing to missing baseline and/or variability data. Any differences reported were not statistically or clinically meaningful, suggesting that models for integrating palliative care were not more effective than control in addressing anxiety.

Multimodal interventions

No studies evaluating multimodal interventions assessed anxiety.

Psychological well-being

Models for integrating palliative care

Two CTs, reported in three articles, assessed the effect of models for integrating palliative care on psychological well-being.37, 38, 70

The two CTs both assessed wider populations including cancer, heart failure, and COPD patients, one over a period of 4 to 9 months and the other over a period of 12 months. 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 combined with patient/caregiver education 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. We were unable to draw conclusions about effect of models for integrating palliative care on psychological well-being due to study limitations.

Multimodal interventions

No studies evaluating multimodal interventions assessed psychological well-being.
Pain

Models for integrating palliative care

One RCT, one CT, and two prospective, cohort studies assessed the effect of models for integrating palliative care on pain.\textsuperscript{37, 38, 65, 67, 68} The RCT evaluated clinician training/education combined with a shared care model in patients with CHF over a period of 6 months (n=314).\textsuperscript{65} The 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 CT also evaluated patient-caregiver training/education combined with a shared care model including patients with COPD, CHF, and cancer and completing assessment at 12 months (n=90).\textsuperscript{37, 38} 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 (n=92).\textsuperscript{67} The other study evaluated the effect of a shared care model on a wider patient population (n=49) over a time period ranging from 2 weeks to 9 months.\textsuperscript{68} Both prospective cohort studies assessed pain with the Edmonton Symptom Assessment Scale (ESAS) (a 10-point scale). In one cohort, pain changed from a mean of 1.34 +/- 2.39 at baseline to 2.04 +/- 2.47 (p=0.04).\textsuperscript{67} In the other cohort, pain changed from a mean (SD) of 3.59 (3.11) to 3.74 (2.57) (no statistics reported).\textsuperscript{68}

None of the differences reported in these studies were clinically meaningful, suggesting that models for integrating palliative care are not effective for pain.

Multimodal interventions

No studies evaluating multimodal interventions assessed pain.

Dyspnea

Models for integrating palliative care

One RCT, one CT, and two prospective cohort studies assessed the effect of models for integrating palliative care on dyspnea.\textsuperscript{37, 38, 65, 67, 68} The RCT (n=314) evaluated clinician training/education combined with a shared care model in patients with CHF over a period of 6 months.\textsuperscript{65} 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 CT (n=90) also evaluated patient-caregiver training/education combined with a shared care model but was conducted over 12 months and included patients with COPD, CHF, and cancer.\textsuperscript{37, 38} 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 interferes (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 limits
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 (n=92). The other study evaluated the effect of a shared care model on a wider patient population (n=49) over a time period ranging from 2 weeks to 9 months. Both prospective cohort studies assessed dyspnea with the Edmonton Symptom Assessment Scale (ESAS) and each worsened with the intervention, although this was not clinically significant. In one cohort, dyspnea changed from a mean of 0.34 +/- 1.06 at baseline to 1.06 +/- 1.95 (p=0.009). In the other cohort, dyspnea changed from a mean (SD) of 1.57 (2.63) to 1.75 (2.24).

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.

The RCT (n=314) evaluated clinician training/education combined with a shared care model over a period of 6 months in patients with CHF. One prospective cohort study evaluated a consultative model on a hemodialysis unit over a period of 6 months (n=92). The other study evaluated the effect of a shared care model on a wider patient population (n=49) over a time period ranging from 2 weeks to 9 months.

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 Edmonton Symptom Assessment Scale (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). In the other cohort, fatigue changed from a mean (SD) of 5.49 (3.16) to 4.98 (2.52).

Differences were not clinically meaningful, suggesting that 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 (n=50).

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, primarily because there was only one small study at high risk of bias.

**Multimodal interventions**

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

**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.\(^{23, 24}\) 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 (n=178). 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.\(^{37, 38, 65, 66, 70}\) One study evaluated the effect of a model for integrating palliative care on rehospitalizations.\(^{71}\)

Two RCTs evaluated the effect of a model for integrating palliative care on hospitalization.\(^{65, 66}\) 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 intervention group and 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).\(^{65}\)

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 intervention group and usual care group was similar between groups (29.4% vs. 29.9%, *p*=0.87).\(^6\)

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.\(^3, \^8\)

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.\(^7\)

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. 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.\(^7\)

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.\(^7\) 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).\(^7\)

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**

Five studies, reported in six articles, evaluated the effect of models for integrating palliative care on advance directive documentation.\(^3, \^8, \^4, \^6, \^7, \^9\)

Two RCTs evaluated the effect of models for integrating palliative care on advance directive documentation.\(^4, \^9\) 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.\(^4\) Any documentation of advance care preferences at 6 months was reported in 65 percent of patients in the intervention group compared with 33
percent in the usual care group (RR 3; 95% CI, 1.13 to 7.94; p=0.02). Physician-level
documentation of advance preference was recorded in 58 percent of patients in the intervention
group compared with 20 percent in the usual care group (RR 2.7; 95% CI, 1.19 to 6.46).

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 (n=186).69 Advance directive (AD) documentation was reported as
three different metrics: 1) median time to completion of first AD between groups, 2) group
differences in the percentage of AD completed at 3 and 6 months, and 3) group differences in
mean number of ADs completed per patient at 3 and 6 months. The median time to completion
of first AD was significantly higher in the usual care group (238 days vs. 46 days, p=0.02). The
group differences in percent of patients completing at least one AD was higher in the
intervention group (69.4% vs. 48.4%; RR 1.53; 95% CI, 1.26 to 1.86; p=0.006). The group
differences in the mean number of advance directives per patient was higher for the intervention
and control groups at 6 months [1.33 (SD 0.98) vs. 0.93 (SD 1.07), p=0.01].

Two CTs, reported in three articles, evaluated the effect of models for integrating palliative
care on AD documentation.37, 38, 70 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.37, 38 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% for
the intervention and 38% for the control group (RR 1.92; 95% CI, 0.74 to 5; p=0.91).

The second 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.70 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 (95% CI, 1.62
to 3.05) times 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.67 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.

Results were consistent across study types and different measurements of outcome. Models
for integrating palliative care were more effective than usual care for increasing AD
documentation (SOE: Moderate).

**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 (n=525).77 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 it is an intermediate, non-patient reported
outcome, but it was reported in a large trial with low risk of bias. Multimodal interventions had little to no effect on advance directive documentation (SOE: Low).

**Costs and resource use**

**Models for integrating palliative care**

One RCT, two CTs, and one prospective cohort study, reported in five articles, assessed the effect of models for integrating palliative care on costs and resource use.\(^{37, 38, 68-70}\)

In the RCT, 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 \(p=0.05\).\(^{37, 38}\)

In the same RCT, 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, \(p=0.03\)).\(^{37, 38}\)

In one CT, costs were assessed at the patient-level six months prior to enrollment and at 3 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 is $4,172 (SD $12,456) \(p=0.29\) (MBGD -3424.42, 95% CI, -13519.98 to 6671.14). The study did not report resource use.\(^{69}\)

In the second 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), 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 number of medical services used between intervention group and usual care group was not significant.\(^{70}\)

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.\(^{37}\) Costs reported in the RCT do not capture long-term evaluation and varying outcomes associated with diagnosis that impact differences between intervention group and usual care group.\(^{69}\) Reporting metrics for
resource use was also inconsistent in terms of type of health services used and frequency of use to draw meaningful conclusions.\textsuperscript{37, 38, 78} Studies varied widely in reporting metrics of outcomes related to cost and resource use 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**

No studies evaluating multimodal interventions assessed costs and resource use.

**Adverse Effects**

**Medication side effects**

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

**Dropouts related to the intervention**

**Models for integrating palliative care**

Only one study, a CT, reported dropouts related to the intervention.\textsuperscript{37, 38} The study reported status at the end of the study period among intervention (n=50) and control (n=40) groups. In both the intervention and control groups, 15 individuals died during the study and 9 individuals were lost to followup, with 66 completing the study (RR 1.33; 95\% CI, 0.64 to 2.72).

We were unable to draw conclusions about the effect of models for integrating palliative care on dropouts related to the intervention, as only one small study reported inconclusive results.

**Multimodal interventions**

No studies of multimodal interventions assessed dropouts related to the intervention.
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 four 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\textsuperscript{48-50} and how clinicians document these discussions (Table 17).\textsuperscript{79} The studies included patients (2 studies, n=18),\textsuperscript{48, 49} caregivers (2 studies, n=38, such as family members),\textsuperscript{49, 50} and non-palliative care ambulatory clinicians (physicians and nurse practitioners) (2 studies, n=21).\textsuperscript{48, 79} One study conducted qualitative observations\textsuperscript{48} and three studies conducted qualitative interviews\textsuperscript{49, 50, 79} (see Appendix D for full study characteristics).\textsuperscript{48}

Shared decision-making tools were considered related to the following conditions: COPD (1 study),\textsuperscript{48} general populations with serious illnesses (1 study),\textsuperscript{79} advanced heart failure [with Left Ventricular Assist Devices (LVADs)] (1 study),\textsuperscript{49} and end-stage renal disease (ESRD) on dialysis (1 study).\textsuperscript{50} The ESRD study was linked to a quantitative effectiveness evaluation of the intervention.\textsuperscript{50} One study was rated as low quality because the overall research methodology, analysis of data, and interpretation of results were insufficiently described.\textsuperscript{48} The remaining three studies were classified as high quality.\textsuperscript{49, 50, 79} All studies used thematic analysis (see Results Appendix D for study details)
<table>
<thead>
<tr>
<th>Author, year</th>
<th>Study and participant characteristics and funding</th>
<th>Intervention description</th>
</tr>
</thead>
</table>
| Dillon, 2017<sup>34</sup> | 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<sup>44</sup> | 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<sup>45</sup> | 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<sup>51</sup> | 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. |

COPD = chronic obstructive pulmonary disease; LVAD = left ventricular assist device; DNR = do not resuscitate; SPIRIT= Sharing Patients’ Illness Representation to Increase Trust.
Table 18: 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

<table>
<thead>
<tr>
<th>Factors for implementation of shared decision-making tools</th>
<th>Clinician/stakeholder and patient/caregiver perceptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>External factors</td>
<td>Not addressed</td>
</tr>
<tr>
<td>Organizational factors</td>
<td>Concerns about implementation during routine care owing to time constraints</td>
</tr>
<tr>
<td>Organizational characteristics</td>
<td>Not addressed</td>
</tr>
<tr>
<td>Collaboration, resources and leadership</td>
<td>Not addressed</td>
</tr>
<tr>
<td>Intervention and implementation characteristics</td>
<td>Intervention:</td>
</tr>
<tr>
<td></td>
<td>• Preferences for grounding in patient and caregiver experiences of illness, rather than general conversations about the end of life*</td>
</tr>
<tr>
<td></td>
<td>• Providing information about the life-limiting nature of the illness*</td>
</tr>
<tr>
<td></td>
<td>• Acknowledge the caregiver’s role and empower and prepare them and open communication with patient*</td>
</tr>
<tr>
<td></td>
<td>• Patients/caregivers: individualize timing to preferences*; clinicians: at time of medical stability</td>
</tr>
<tr>
<td></td>
<td>• Should be time-efficient, specific, and succinct</td>
</tr>
<tr>
<td></td>
<td><strong>Implementation:</strong></td>
</tr>
<tr>
<td></td>
<td>• Integration into clinical workflow</td>
</tr>
<tr>
<td></td>
<td>• Need for standardized workflows</td>
</tr>
<tr>
<td>Clinician/team characteristics</td>
<td>Advance care planning should be conducted by clinician who knows the patient best</td>
</tr>
<tr>
<td>Patient/caregiver characteristics</td>
<td>Not addressed</td>
</tr>
</tbody>
</table>

The studies we identified evaluated the implementation of advance care planning tools alongside clinical workflows and assessed overall patient and caregiver experiences of advance care planning experiences. One study described the process of how clinicians currently incorporate documentation of advance care planning into the electronic health record.79 Two studies evaluated iterations of the SPIRIT intervention, a nurse-led intervention consisting of nurse-facilitated discussions with patients and their caregivers regarding various advance care planning topics.49, 50 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.48

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.49 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.49, 50 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).50 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.50

**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.49 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.49 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.48 Clinicians identified the need for standardized workflows to incorporate discussions, such as those in the SPIRIT interventions, into routine care.48 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.48, 79

**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,48 end-stage renal disease,50 and advanced heart failure.49

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.49, 50 Patients and caregivers felt that the timing of these conversations should be individualized to specific patients and caregivers;49 some expressed a desire for initiation of these conversations earlier in the disease course.49 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.48
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?

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.61 This study used a “train-the-trainer” model, which consisted of training clinicians (n=22) within three large healthcare systems to subsequently train non-palliative care clinicians (n=297) to use the Guide within their respective institutions (Table 19) (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 19. Characteristics of qualitative studies for shared decision-making tools

<table>
<thead>
<tr>
<th>Author, year</th>
<th>Study and participant characteristics and funding</th>
<th>Intervention Description</th>
</tr>
</thead>
</table>
| Paladino, et al., 201961 | 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 (“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 follow-up 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, end-stage renal disease, and advanced heart failure.

**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 nine studies investigating models for integrating palliative care and multimodal interventions in ambulatory settings from both patient and clinician perspectives (Table 20). These studies evaluated barriers and facilitators from both practical and implementation frameworks, in addition to the overall patient experience. The studies included patients (4 studies, n=113), non-palliative care ambulatory physicians (3 studies, n=51), and clinical team members on a palliative care advisory group (n=11). One study 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 and eight studies conducted individual qualitative interviews (see Results Appendix D for full study details).
characteristics). All studies used thematic analysis (one study reported “modified grounded theory,” which, on further examination, appeared to be better characterized as a thematic analysis.80) Six of nine articles were rated as high quality.72, 73, 76, 81-83 Three articles were rated as low quality because the overall research methodology, analysis of data, and interpretation of results were insufficiently described.74, 75, 80 Owing to these issues, it was also difficult to determine whether the conclusions flowed from the analysis and interpretation of the data.

Table 20. Characteristics of qualitative studies for models and multimodal interventions

<table>
<thead>
<tr>
<th>Author, year</th>
<th>Study and participant characteristics and funding</th>
<th>Intervention description</th>
</tr>
</thead>
</table>
| Nowels, 201681 | ```
n=20 clinicians
- Multi-site, primary care,
- Primary care clinicians
- Non-profit funding
``` | No intervention evaluated.
(Perceptions of palliative care in primary care) |
| Scherer, 201883 | ```
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, 201472 | ```
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
``` | Control group: Psychospiritual intervention
- Intervention: The Collaborative Care to Alleviate Symptoms and Adjust to Illness (CASA) intervention included 1) nurse phone visits involving structured symptom assessments and guidelines to alleviate breathlessness, fatigue, pain, or depression; 2) structured phone counseling targeting adjustment to illness and depression, if present; and 3) weekly team meetings with a palliative care specialist, cardiologist, and primary care physician focused on medical recommendations to primary care physicians, or nurse practitioners to improve symptoms. |
| Bekelman, 201682 | ```
n=17 clinicans 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) |
| Lakin, 201973 | ```
n=17 primary care clinicians
- Multi-site, primary care clinics
- Primary care physicians, nurses, and social workers
- Non-profit 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. |
<table>
<thead>
<tr>
<th>Author, year</th>
<th>Study and participant characteristics and funding</th>
<th>Intervention description</th>
</tr>
</thead>
</table>
| Hobler, 2018<sup>80</sup> | n=48 patients  
• Single-site, cystic fibrosis clinic  
• Cystic fibrosis patients  
• Non-profit funding | No intervention evaluated.  
(Evaluating palliative care and advance care planning needs and clinicians’ potential roles) |
| Long, 2014<sup>14</sup> | n=13 patients  
• Single-site, pulmonary specialty clinic  
• Patients with COPD  
• Non-profit 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. |
| Rabow, 2003<sup>13</sup> | n=35 patients  
• Single-site, primary care  
• COPD, CHF, and cancer patients  
• Non-profit funding | Intervention: Interdisciplinary palliative care team providing outpatient palliative care consultation, case management, psychological support, chaplaincy, caregiver training, medication review, and support groups. |
| Goff, 2019<sup>96</sup> | 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. |

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.

Table 21. Integrative review results on the qualitative evidence for components and characteristics of models for integrating palliative care in ambulatory settings

<table>
<thead>
<tr>
<th>Key components of delivery of integrated palliative care</th>
<th>Patient/caregiver perceptions of key components of delivery of integrated palliative care</th>
<th>Clinician/stakeholder perceptions of key components of delivery of integrated palliative care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introducing palliative care</td>
<td>• Varied: preference for the intervention to be provided after diagnosis, vs. beginning of the end of life</td>
<td>• Should be provided to terminally ill patients or preterminal stages</td>
</tr>
</tbody>
</table>
| Communication                                          | • Facilitating better communication about difficult issues  
• Listening with compassion  
• Feel heard and be “seen” | • Paying special attention to clinician-patient relationships  
• Clearly structuring interventions aiming to change the way the system drives serious illness communication |
| 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 22. Integrative review results on the qualitative evidence for how, when and for which patients models for integrating palliative care could best be implemented

<table>
<thead>
<tr>
<th>Factors for implementation of models</th>
<th>Clinician/stakeholder and patient/caregiver perceptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>External factors</td>
<td>Not addressed</td>
</tr>
</tbody>
</table>
| 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 | Collaboration:  
• Creating shared ownership  
• Understanding of specific stakeholder needs  
• Paying special attention to interprofessional relationships  
Resources:  
• Lack of clinician time  
• Cost of paying for visits  
• Difficulty scheduling sessions within busy schedules  
• Need to justify any additional personnel costs  
Leadership:  
• Collaborate with local leaders to align palliative care with local programs |
| Intervention and implementation characteristics | Intervention:  
• 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*  
Implementation:  
• 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 |
| Clinician/team characteristics       | • Development of a dedicated, interdisciplinary team as potentially being beyond the capabilities of some healthcare institutions  
• Advanced Practice Nurses (APNs) were 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

Two 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 identify necessary improvements for future iterations of the intervention, and 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. Both interventions were perceived as feasible and helpful by participants and studies highlighted several key barriers and facilitators to implementation.

One study evaluated the multimodal intervention “Shared Decision-Making and Renal Supportive Care” (SDM-RSC), an intervention designed to improve advance care planning for patients with end-stage kidney disease on hemodialysis. This intervention was perceived as feasible and helpful by participants and the study highlighted several key barriers and facilitators to implementation. The study authors noted 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.

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. 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. The interventions delivered by Advanced Practice Nurses (APNs) were feasible and patients perceived them to be beneficial. 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. Among interventions led by nurses or APNs, patients saw the nurses as advocates.

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. In another study, patients similarly commented on the structure of the survey, which they generally deemed as being burdensome and repetitive. 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.
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.  

**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, 2) establishing clear professional roles and responsibilities, 3) paying special attention to specific stakeholder needs and relationships, and 4) clearly structuring interventions aiming to change the way our system drives serious illness communication. 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 health care institutions.

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 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. To effectively adopt and scale up 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 clinicians (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.

**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, yet another identified a preference for the beginning of the end of life. 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.

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

In summary, models to integrate palliative care in ambulatory settings include a variety of components and have been implemented among patients with COPD,74 end-stage renal disease,76 and advanced heart failure.72 These models included communication strategies that facilitate shared decision-making,72, 76 defined roles and responsibilities for each team member,73 and structured workflows that promote easier integration.73 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 shared decision-making tools for primary care and advanced heart failure, but evidence was insufficient to draw conclusions about the effectiveness of the combined interventions. 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 options offered to all patients with serious illnesses.

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

Although a variety of relevant patient and caregiver education tools are available as resources, none have been evaluated for effectiveness or implementation for integrating palliative care into ambulatory care. Only one study of an integrated palliative care model explicitly included patient/caregiver education as a component, and we were unable to draw conclusions about the effectiveness of this component. None of the implementation studies included patient/caregiver education. 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 decision-making tools 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 (SOE: Low), but we were unable to draw conclusions about patient depression or caregiver satisfaction. In Table 23, 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 evaluated involved additional personnel and resources.

Table 23. Overall integrative synthesis for shared decision-making tools

<table>
<thead>
<tr>
<th>Factors for implementation of shared decision-making tools</th>
<th>Summary findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>External factors</td>
<td>• None of the resources or studies addressed external factors; clinician/stakeholder Key Informants noted performance measures as a potential key factor.</td>
</tr>
<tr>
<td>Organizational factors</td>
<td>• Implementation studies noted concerns about implementation during routine care owing to time constraints; effectiveness studies were not conducted as part of routine care.</td>
</tr>
<tr>
<td>Organizational characteristics</td>
<td>• Effectiveness studies were conducted in both academic and community settings.</td>
</tr>
<tr>
<td>Collaboration, resources, and leadership</td>
<td>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.</td>
</tr>
<tr>
<td>Intervention and implementation characteristics</td>
<td>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.</td>
</tr>
<tr>
<td>Clinician/team characteristics</td>
<td>• 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</td>
</tr>
<tr>
<td>Patient/caregiver characteristics</td>
<td>• None of the resources, studies, or Key Informants addressed collaboration.</td>
</tr>
</tbody>
</table>

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

A variety of clinician education and training resources for non-palliative care clinicians are available for integrating palliative care into ambulatory care, but only one implementation study and one model effectiveness study explicitly evaluated this component. Both
clinician/stakeholders and patient/caregiver Key Informants expressed that more education and training is needed for ambulatory care clinicians. Patients/caregivers 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 are more effective than usual care for depressive symptom scores and increasing advance directive documentation (SOE: Moderate for both) but models were not effective for HRQOL (SOE: Moderate). We were unable to draw conclusions for patient satisfaction. Five of the nine studies about models for integrating palliative care evaluated a shared care model, one used a consultative model, and four used integrating care coordinators or social workers into practice (one combined this with shared care). 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 (Table 24), but we were unable to draw specific conclusions about effects of specific components, characteristics, and factors or multicomponent 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 25).

Table 24. Overall integrative synthesis for components and characteristics of models for integrating palliative care and multimodal interventions

<table>
<thead>
<tr>
<th>Key components and characteristics of delivery of integrated palliative care</th>
<th>Summary findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introducing palliative care</td>
<td>• Included generally in interventions as either shared care (five of nine) and/or integrating care coordinators or social workers into practice (four of nine interventions) • Patient and clinician preferences for timing varied</td>
</tr>
<tr>
<td>Communication</td>
<td>• 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</td>
</tr>
<tr>
<td>Addressing symptoms</td>
<td>• Focus on addressing unmet needs • Symptoms surveys should be focused, as often burdensome and repetitive</td>
</tr>
<tr>
<td>Psychosocial care</td>
<td>• Involvement of interdisciplinary team care coordinators, including nurses and social workers, including psychosocial care, was key to many interventions</td>
</tr>
<tr>
<td>Care planning</td>
<td>• 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</td>
</tr>
<tr>
<td>Followup</td>
<td>• Interventions were generally longitudinal or included reminders Key components included: • Linking to community resources • Able to offer individualized solutions</td>
</tr>
</tbody>
</table>
Table 25. Overall integrative synthesis for implementation factors of models for integrating palliative care and multimodal interventions

<table>
<thead>
<tr>
<th>Factors for implementation of models for integrating palliative care</th>
<th>Summary findings</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>External factors</strong></td>
<td></td>
</tr>
<tr>
<td>• Payment mechanisms and performance measures were perceived as important.</td>
<td></td>
</tr>
<tr>
<td><strong>Organizational factors</strong></td>
<td></td>
</tr>
<tr>
<td>• Minimizing patient burden was perceived as important to successful implementation.</td>
<td></td>
</tr>
<tr>
<td><strong>Organizational characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>• Using existing practice improvement models, strategies, and prioritization was perceived as important to successful implementation.</td>
<td></td>
</tr>
<tr>
<td><strong>Collaboration, resources, and leadership</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Collaboration</strong></td>
<td></td>
</tr>
<tr>
<td>• Models should build on shared ownership and understanding of specific stakeholder needs.</td>
<td></td>
</tr>
<tr>
<td>• Models benefit from attention to interprofessional relationships.</td>
<td></td>
</tr>
<tr>
<td><strong>Resources</strong></td>
<td></td>
</tr>
<tr>
<td>• Issues with models include clinician time, costs, and scheduling challenges.</td>
<td></td>
</tr>
<tr>
<td>• Results of effectiveness for costs and resource use were inconsistent.</td>
<td></td>
</tr>
<tr>
<td><strong>Leadership</strong></td>
<td></td>
</tr>
<tr>
<td>• Involvement can help align palliative care with local programs.</td>
<td></td>
</tr>
<tr>
<td><strong>Intervention and implementation characteristics</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Intervention</strong></td>
<td></td>
</tr>
<tr>
<td>• Clarifying goals was key, and low-burden interventions were perceived as easier to implement and preferred by patients.</td>
<td></td>
</tr>
<tr>
<td>• A wide variety of characteristics were included in interventions, precluding specific conclusions.</td>
<td></td>
</tr>
<tr>
<td><strong>Implementation</strong></td>
<td></td>
</tr>
<tr>
<td>• Addressing stakeholder needs and relationships is key.</td>
<td></td>
</tr>
<tr>
<td>• Clarify roles, responsibilities, and costs of interventions.</td>
<td></td>
</tr>
<tr>
<td><strong>Clinician/team characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>• Nurses were particularly perceived as useful.</td>
<td></td>
</tr>
<tr>
<td>• Clinician/team involvement in interventions varied and was often not specified, precluding specific conclusions.</td>
<td></td>
</tr>
<tr>
<td>• Interdisciplinary care is costly and often not practical outside of funded grants.</td>
<td></td>
</tr>
<tr>
<td><strong>Patient/caregiver characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Not addressed</td>
<td></td>
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</tbody>
</table>
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 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 non-palliative care clinicians; and models for integrating palliative care and multimodal interventions. We identified 45 web resources, 16 quantitative effectiveness studies, and 14 qualitative implementation studies relevant to the integration of palliative care into ambulatory care for patients 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 goals-of-care communication and advance care planning. We found that these tools may be effective for improving patient satisfaction (SOE: Low) and advance directive documentation (SOE: Low). 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 non-palliative 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. Models for integrating palliative care into ambulatory care were associated with better depressive symptom scores than usual care and were effective for increasing advance directive documentation (SOE: Moderate for both) but were not effective for patient HRQOL (SOE: Moderate). Patient perceptions of appropriate timing to initiate palliative care varied. Almost no studies reported adverse effects, burdens, or dropouts related to the interventions. For costs and resource use, results were inconsistent. Components of interventions varied widely 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. The key U.S. evidence-based palliative care guideline, the National Consensus Project for Quality Palliative Care, does not recommend standard palliative care.
identification criteria or standards for integration into ambulatory care. 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.

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 ACP. 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. 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.

Other broader reviews of models for integrating palliative care have addressed populations with cancer, 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.” 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. 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. As in our review, this review also found that economic analyses were poorly defined.

Other recent systematic reviews of palliative care across settings have found evidence for small effects on the outcome of advance care planning and not for most other symptoms as in our review, but did also find small effects on HRQOL and satisfaction. 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. 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. A 2016 systematic review of the effect of a wide variety of palliative care interventions on economic outcomes found no evidence for beneficial effects.

**Strengths and Limitations**

The evidence for integration of palliative care into ambulatory care for patients 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. 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 advance care planning, but not 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 they were implemented, 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 unable to conduct any meta-analyses, even for outcomes for which we identified three or more studies. 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, COPD, and 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 key U.S. national palliative care, health professional and consumer organizations and those posted on the web, and does not include the wide variety available through many health systems, individual states, and other 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. Although we used accepted standards for clinically meaningful differences, 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 advance care planning 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.97, 98

Models mainly addressed shared care or incorporating care coordinators or social workers into care as methods of integration. Other model types such as telehealth; coaching; and stepped care, where patients with serious illness initially receive care from non-palliative care clinicians and are referred to palliative care specialists depending on need, have been evaluated in feasibility testing or have ongoing clinical trials.99, 100 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 advance care planning 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 focused on approaches of shared care and incorporating care coordinators or social workers into practice and interdisciplinary care, particularly with nurses, was a key factor.

In terms of future research, 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 or chosen in a stepped fashion. 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, choice of outcomes validated for palliative care, outcome measurement, and analysis.\textsuperscript{101-103} Similarly, qualitative implementation studies should follow established criteria for quality qualitative research.\textsuperscript{13, 104} 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.\textsuperscript{104, 105} 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, particularly given the growing needs of the aging U.S. population.

In terms of answering the decisional dilemma and implications for the AHRQ 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, \textit{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.\textsuperscript{106, 107} For clinician-patient communication about palliative care, given that frequent and often detailed conversations about the end of life are needed, the \textit{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 non-palliative care clinicians. For policy, the report recommends that the health care 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.\textsuperscript{107} 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.\textsuperscript{108}

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 delivery including telehealth 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 integrating palliative care into ambulatory care for serious life-threatening chronic illness or conditions other than cancer, advance care planning shared decision-making tools may increase patient satisfaction and advance directive documentation. Models for integrating palliative care may be effective for symptoms of depression, although differences were not clinically meaningful, and increasing advance directive documentation, but not for addressing HRQOL. Further research is particularly needed on identification of patients; educational materials for patients, caregivers, and clinicians; and implementation of specific components, characteristics, and factors in models, and needs to address the real-life and most important concerns of those impacted by serious illness and conditions. Fundamental changes in the healthcare system are needed to enable wider dissemination and access to ambulatory care that can better meet the needs and improve HRQOL for these patients and their caregivers.
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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