

Integrating Palliative Care in Ambulatory Care of Noncancer Serious Illness

Evidence Summary



Main Points

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

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



Background and Purpose

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



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



Methods

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



Results

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

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

We then integrated these parts for each Key Question.

We included 46 Web resources, 20 quantitative effectiveness studies and 16 qualitative implementation studies. We identified no mixed-methods studies.

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

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

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

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

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

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

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

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

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

- The models evaluated for integrating palliative care were not more effective than usual care for patient health-related quality of life (strength of evidence [SOE]: Moderate).
- The models evaluated for integrating palliative care may have little to no effect compared with usual care for overall symptom burden (SOE: Low) and were not more effective than usual care for depressive symptom scores (SOE: Moderate).
- The models evaluated for integrating palliative care may have little to no effect compared with usual care on patient satisfaction (SOE: Low), and no studies addressed caregiver satisfaction.
- The models evaluated for integrating palliative care were more effective than usual care for increasing advance directive documentation (SOE: Moderate).
- For utilization, the models evaluated for integrating palliative care were not more effective than usual care for reducing hospitalizations; we were unable to draw conclusions about most other aspects of utilization or cost and resource use.
- Multimodal interventions may have little to no effect on increasing advance directive documentation (SOE: Low), and no studies addressed the effect of multimodal interventions for other critical (graded) outcomes.
- Multimodal interventions (including combinations of identification of patients, education for patients and caregivers, shared decision-making tools, and education for nonpalliative care clinicians) had little to no effect on advance directive documentation (SOE: Low) and no studies addressed the effect of multimodal interventions for other critical (graded) outcomes.
- A wide variety of components, characteristics, and factors have been implemented in models for integrating palliative care and are perceived as important by patients, caregivers, clinicians, and stakeholders, but we were unable to draw conclusions about which, if any, of these influence effectiveness or implementation.
- Clinician/stakeholder Key Informants had a number of suggestions for implementation of models and multimodal interventions for integrating palliative care, including integration into and simplification of workflows and documentation, leveraging delivery systems and payment mechanisms, use of interdisciplinary care, and integrating quality measurement and improvement.
- Patient/caregiver Key Informants indicated that clinicians should integrate palliative care into routine care, and that primary care is a key opportunity to introduce it.



Strengths and Limitations

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



Implications and Conclusions

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

Full Report

Dy SM, Waldfogel JM, Sloan DH, Cotter V, Hannum S, Heughan J, Chyr L, DeGroot L, Wilson R, Zhang A, Mahabare D, Wu DS, Robinson KA. Integrating Palliative Care in Ambulatory Care of Noncancer Serious Chronic Illness. Comparative Effectiveness Review No. 237. (Prepared by the Johns Hopkins University Evidence-based Practice Center under Contract No. 290-2015-00006-I.) AHRQ Publication No. 21-EHC002. Rockville, MD: Agency for Healthcare Research and Quality; February 2021. DOI: <https://doi.org/10.23970/AHRQEPCCER237>. Posted final reports are located on the Effective Health Care Program [search page](#).

