



## *Comparative Effectiveness Review Disposition of Comments Report*

### **Research Review Title:** Integrating Palliative Care in Ambulatory Care of Noncancer Serious Chronic Illness

Draft report available for public comment from August 5, 2020 to September 18, 2020.

**Research Review Citation:** 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.  
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### **Comments to Draft Report**

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Comments on draft reports and the authors' responses to the comments are posted for public viewing on the Web site approximately 3 months after the final report is published. Comments are not edited for spelling, grammar, or other content errors. Each comment is listed with the name and affiliation of the commentator, if this information is provided. Commentators are not required to provide their names or affiliations in order to submit suggestions or comments.

This document includes the responses by the authors of the report to comments that were submitted for this draft report. The responses to comments in this disposition report are those of the authors, who are responsible for its contents, and do not necessarily represent the views of the Agency for Healthcare Research and Quality.



## Summary of Peer Reviewer Comments and Author Response

This research review underwent peer review before the draft report was posted for public comment on the EHC website.

Below is a list of common themes brought up by the commenters.

1. Better definition/discussion of the role of “palliative care” in the interventions and its role in ambulatory care
2. Lack of sufficient clarity on how websites were reviewed and inclusion criteria
3. Lack of sufficient discussion on types of models
4. More clarity on the emphasis on advance care planning

These changes made to the report to address these comments:

1. Definition/discussion of the role of “palliative care” in the interventions: We have clarified with the use of the terms “palliative clinicians” and “better integrate palliative care” and defining and using terms about shared and consultative care throughout the report.
2. What websites were reviewed and inclusion criteria: We clarified and added additional details to the methods, methods appendix, results and table titles to emphasize the focus on inclusion of U.S. national websites and make clearer the long list of websites that were reviewed and the lists available in the appendices.
3. Types of models: We have clarified and incorporated the model types more throughout the report and in the discussion
4. Emphasis on advance care planning: We have emphasized throughout the report that the shared decision-making tools found were all on advance care planning; worked to standardize more the language in the report on advance care planning, goals of care documentation, and advance directives; and expanded on the implications of these findings in the discussion.



Comment No.	Commentator & Affiliation	Section	Comment	Response
1.	<b>Public Reviewer #1</b>	General	<p>The review within its parameters and scope is fine, but it is built on a very seriously flawed conceptual base. Palliative care as a specialty was developed mostly during the 1990's. It is simply not the case that there was no palliative care before then, or that persons treated by ordinary physicians are not receiving palliative care even now. Indeed, it is a distortion of the period from about 1970 to 2000 that the society and the professions in medical care perceived themselves as involved in diagnosis and treatment mainly. The older tradition sought "palliation" virtually always. So, "integrating palliative care into ambulatory care" is not actually captured by studies that look only at palliative care programs and specialists. The ordinary primary care physician has been and should be doing a great deal of palliation.</p> <p>In short, it would be so much better if the scope of the work were clearly designated as being to attend to palliative care specialty programs, not to "palliative care." Then the title would be something like "Programs to formally integrate palliative care specialists and teams into ambulatory care of non-cancer serious chronic illness" - and it would be obvious that some palliative care is going on outside of these programs.</p>	<p>Thank you for this very valuable point and perspective. We considered this carefully in the revision of the report and have reframed, where appropriate, as "palliative care clinicians" (many of these were not specialists or teams but clinicians providing some palliative care-type services). Some of the interventions did not actually provide additional staff but integrated training and palliative care systems interventions into practice.</p> <p>We have changed the language to "better integrate palliative care" in some places in the Introduction and throughout the report.</p> <p>We have also changed the language in defining consultative care: "(where non-palliative care ambulatory clinicians meet and support common palliative care needs, with referrals to specialty palliative care when needs are more complex or are not being met)</p>



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2.	Public Reviewer #1	General	<p>Consider that a review of the role of cardiology specialists in the care of a very common heart problem like hypertension would assume that a great deal of hypertension care is being done by others. The questions would be whether adding specialty clinicians and teams substantially improved upon that background rate.</p> <p>This is terribly insidious as a problem in modern medicine. More and more, this sort of framing is making it seem that symptoms, care planning, and end of life care fall to “palliative care” and hospice – but they should be the heart of primary care.</p>	<p>Thank you, we greatly appreciate this perspective. We have adjusted some of the language in the discussion and throughout to address this point, using terms such as “better integrate palliative care approaches” rather than “integrate palliative care” in the conclusions so as not to assume that this is not already present and only in the scope of palliative care clinicians.</p>
3.	Public Reviewer #2	Question 1	<p>This is well done and more emphasis on outpatient palliative care is important in care models, clinical training, and research. I agree with the conclusions as stated. Many times it is difficult to include new models of care in AHRQ evaluations, however in the spirit of sharing new ideas which help inform best practices, I have included a recent publication from my group utilizing risk assessment to target advanced directive discussions in an outpatient geriatric practice at the VA.</p>	<p>Thank you; unfortunately this article is not in the peer-reviewed literature (i.e., was not included in one of the indexed databases we searched) and we focused our grey literature search on key national organizations.</p>
4.	Public Reviewer #2	Question 3	<p>Consider including descriptive implementation reports, or clinical demonstration projects to display creative new models of care supporting outpatient palliative care practice. Well many of these have not been evaluated for effectiveness, they have demonstrated feasibility. Perhaps a table of potential new models of outpatient palliative care practice would help stimulate adoption and evaluation of these models.</p>	<p>We did consider and search for qualitative implementation studies. Unfortunately, demonstration projects not formally evaluated for implementation or effectiveness were outside the scope of this review; we have expanded on the limitations for this point.</p>
5.	Public Reviewer #2	Question 5	<p>Consider expanding the discussion to include potential models of ambulatory palliative care worthy of further promotion and study. This would be a help to the field.</p>	<p>We have added discussion of the three types of models of ambulatory care addressed in this report.</p>



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6.	Public Reviewer #2	Question 7	The report is accurate but only focuses on effectiveness. To expand and discuss implementation requirements, and how they may address gaps in care based on your literature review, would be beneficial to the field.	We have addressed implementation through the qualitative and integrative sections of the report.
7.	Public Reviewer #2	Question 10	Article suggestion: Outpatient–Focused Advance Care Planning: Telehealth Consultation for Geriatric Primary Care Patients	Thank you for the suggested article on a valuable initiative. Unfortunately, this article does not meet inclusion criteria (not on a shared decision-making tool and no control group).
8.	Public Reviewer #3	Question 4	Was the readmission rate of patients that received ambulatory advanced care planning lower than those that did not?	None of the studies included the outcome of readmissions.
9.	Public Reviewer #3	Question 7	What was the sample ratio of Medicare to private insurance?	Unfortunately, this was not addressed in many of the studies.
10.	Public Reviewer #4	Question 7	I consider myself a palliative care enthusiast so I found this review extremely helpful. I feel the authors did an excellent job reviewing literature for non-cancer-related illnesses and palliative care use. I feel lack of specific review on liver diseases is a significant omission. One significant paper that I would like to bring to your attention is “Benefit of Early Palliative Care Intervention in End-Stage Liver Disease Patients Awaiting Liver Transplantation” by Alexandra Baumann. An early palliative care intervention in this patient cohort was associated with statistically significant improvement in pruritus, Well-being, appetite, anxiety and fatigue.	Thank you – this article did not meet inclusion criteria as there was no control group.
11.	Public Reviewer #4	Question 9	It is an exhaustive review so it is very long but totally worth it.	Thank you.



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12.	<b>Public Reviewer #5</b>	ES/Introduction	<p>The initial sections of this report effectively describe AHRQ’s rationale for and approach to this work. A few additional clarifications would be helpful for the reader:</p> <ul style="list-style-type: none"> <li>a. Providing definitions for some of the key terms in the body of the report. While we recognize that these are included in Appendix A, certain terms (specifically “ambulatory settings” and “primary palliative care”) are central to understanding the report and referenced frequently enough that it would be helpful to clarify these upfront.</li> <li>b. Specifying the groups of key informants rather than referring to them “end-users,” particularly since one of the groups is patients and caregivers.</li> <li>c. Providing more detail on the decision to exclude cancer, including references to the existing systematic reviews that informed this decision. Facilitating access to these resources could give the reader a more comprehensive understanding of the current evidence supporting palliative care delivery in the ambulatory care setting, particularly since the evidence base supporting non- cancer palliative care is at an earlier stage.</li> <li>d. Specifying the focus on adults age 18+ upfront, including in the structured abstract.</li> </ul>	<ul style="list-style-type: none"> <li>a. We did not use the term “primary palliative care” in the report to reduce confusion, but used the term “non-palliative care clinicians”.</li> </ul> <p>Great point; we have added in the Introduction that ambulatory settings particularly refers to clinicians’ offices.</p> <ul style="list-style-type: none"> <li>b. The term “end-users” is the standard AHRQ language for the front section of the report. The names of the Key Informants will be listed in the final unblinded published report.</li> <li>c. We have added the key reference to the Introduction (more detail is also provided in the discussion).</li> <li>d. Great point; we have changed wording to “adults” in the abstract and several places.</li> </ul>



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13.	<b>Public Reviewer #5</b>	Methods	<p>a. It would be helpful to have more details about the key informants regarding aspects such as discipline (e.g., was chaplaincy or pharmacy represented), geography, and diagnosis/specialty (if applicable).</p> <p>b. From this section and the Appendices, it was relatively clear why certain resources were excluded from the B (effectiveness) and C (implementation) series of questioning; however, it was difficult to find the selection criteria for series A (what is available). Without that, we identified some notable omissions (described further in the next section) without understanding why they were excluded.</p>	<p>a. Key Informants comprised patients and caregivers, physicians, nurses, social workers, and public health experts. They represented a variety of institutions and organizations (i.e., clinical practices, family practice, professional organizations, policy organizations, and payors from across the United States). A full list of key informants will be published in the final report document.</p> <p>b. Thank you for your comment. Please find the selection criteria for series (or part) (a) in Appendix A: Methods (eligible web resources had to meet all criteria and be specifically relevant to integrating palliative care into ambulatory care for non-cancer serious chronic illness or conditions). We reviewed U.S. national websites where we had either free access or memberships, and reviewed available descriptions of materials on the websites. We have added text to clarify the eligibility criteria.</p>

13.	<b>Public Reviewer #5</b>	Results	<p>A majority of the comments in this section reflect our limited understanding of how AHRQ identified and included or excluded available resources. Several of the websites/resources we provide below are listed in Appendix B with the exclusion criteria “No resources found.” It would be helpful to further describe what is meant by this, since these resources offer rich information on clinician training and/or patient/caregiver educational materials. Absent that, our feedback on this section is as follows:</p> <p>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?</p> <ul style="list-style-type: none"> <li>a. CAPC is pleased to develop and/or curate many tools that will support improved palliative care access and delivery across all care settings. However, we want to clarify that we are not the developers or stewards for many of the resources or interventions listed in Table 4. We would be happy to work with AHRQ to ensure that these resources are properly attributed.</li> <li>b. There are many additional 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. These include (but are not limited to):</li> <li>c. California Health Care Foundation (CHCF) “Weaving Palliative Care</li> </ul>	<p>Thank you for this comment. We have worked to clarify in several places the inclusion criteria and that we focused on integrating palliative care into ambulatory care for serious illness and conditions; we did not include general palliative care resources that did not include this content. We reviewed these palliative care resources that were relevant as listed in detail in the appendix and noted in the methods (see Methods Appendix A-2 for full list of websites searched). To clarify, “no resources found” means that the resources did not meet our inclusion criteria or were linked to a secondary site or another organization.</p> <p>a. Table 4 provides available resources and descriptions of materials on the websites. We understand that CAPC is not the developer or stewards for many of the resources of interventions listed and we have added a footnote to the table to explicitly make this note. The CAPC website did not list references for these resources.</p> <p>b.&amp; c. Thank you for your comment. We have double-checked this list for inclusion. This is an important resource, however, per our inclusion criteria described in the methods, we included national and federal government web resources. State-specific (CHCF) resources were outside the scope of this review. We have emphasized our eligibility criteria in several places, including that we limited consideration to US national resources. This is also noted in the limitations.</p>
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			<p>into Primary Care: A Guide for Community Health Centers.</p> <p>d. American Academy of Hospice and Palliative Medicine (AAHPM)“Primer of Palliative Care, 7th Edition).</p> <p>e. Hospice and Palliative Nurses Association( HPNA) Competencies for RNs and APRNs.</p> <p>f. HPNA and the American Nurses Association (ANA) Call to Action.xviii</p> <p>g. American Heart Association( AHA) and American Stroke Association (ASA) Policy</p>	<p>c. (see b above)</p> <p>d. Thank you for your comment. This is a valuable resource, however, it is a general palliative care resource and there was no content on the website specific to integrating palliative care for ambulatory care, and it is not publicly available for review.</p> <p>e. This is a valuable resource, however, it is a general palliative care resource and there was no content on the website specific to integrating palliative care for ambulatory care, and it is not publicly available for review.</p> <p>f. The ANA/ HPNA position paper is valuable however, we focused on integrating palliative care into ambulatory care for serious illness and conditions. We included palliative care position statements that were specifically relevant to our key questions. We have now added this position paper/webpageto the excluded webpage list.</p> <p>g. Thank you for your comment. While we included clinical guidelines and position statements, we did not include policy statements; we reviewed this again carefully and confirmed that it was not specifically relevant to this review – it is included on the excluded webpage list.</p>



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14.	<b>Public Reviewer #5</b>	Results	<p>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?</p> <p>Additional resources to support patients and caregivers in understanding what palliative care is and where they can access it include, but are not limited to:</p> <ul style="list-style-type: none"> <li>a. GetPalliativeCare.org, the top web-based search result for “palliative care” that includes information on how palliative care can be integrated into treatment for dozens of disease types, regardless of where the patient receives treatment.</li> <li>b. National Institute on Aging, which describes the palliative care intervention and clarifies that it can be provided in “hospitals, nursing homes, outpatient palliative care clinics and certain other specialized clinics, or at home.”</li> <li>c. Many states department of health or similar websites (e.g., Kansas, Nebraska), that have legislatively-mandated palliative care pages with patients/caregiver-focused information on services and access.</li> </ul>	<ul style="list-style-type: none"> <li>a. Thank you for noting this website. We had reviewed this previously as noted on the website list. We carefully reviewed and reconsidered and now have added the GetPalliativeCare.org website to our list of webpage resources.</li> <li>b. Thank you for this comment. This National Institute of Aging site is in our current list of website resources.</li> <li>c. Thank you for your comment. This is an important resource, however, per our inclusion criteria described in the methods, we included national government web resources. State-specific (Kansas, Nebraska) resources were outside the scope of this review. We have emphasized in several places eligibility criteria, including that we focused on US national resources. This is also noted in the limitations.</li> </ul>



15.	<b>Public Reviewer #5</b>	Results	<p>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?</p> <p>Additional (setting agnostic) training and educational materials for non-palliative care clinicians on palliative care principles and practices include, but are not limited to:</p> <ul style="list-style-type: none"> <li>a. CAPC’s operational training, particularly “Designing an Office or Clinic Palliative Care Program and clinical training which is appropriate for clinicians of all disciplines working across care settings. Clinical courses include communication skills, pain and symptom management, and relief of suffering across the trajectory (e.g., dementia, chronic obstructive pulmonary disease, and heart failure), among others</li> <li>b. VitalTalk and Ariadne Labs’ Serious Illness Care which offer evidence-based training to empower clinicians to communicate about serious illnesses and elicit patients about their goals, values, and wishes.</li> <li>c. ELNEC and EPEC which educates healthcare professionals on the essential clinical competencies of palliative and end-of-life care.</li> <li>d. The Conversation Project and Respecting Choices, which focus on helping clinicians and patients/caregivers discuss wishes for care through the end of life.</li> <li>e. Certificate programs such as those offered by the California State University Shiley patients/caregivers discuss wishes for care through the end of life. Institute for Palliative Care, University of Maryland,</li> </ul>	<ul style="list-style-type: none"> <li>a. We appreciate your comments and have double- checked these resources. We did not include general palliative care resources or educational materials that were not specifically relevant to our key questions about integrating palliative care.</li> <li>b. through f. We have double-checked this list for inclusion – thank you. These are valuable resources, however, these are general palliative care resources r not US national resources , there was no content on their websites specific to integrating palliative care for ambulatory care and/or there was no information that was publicly available for review. We did specifically note that we excluded ELNEC as not relevant to this topic.</li> </ul> <p>The Serious Illness Care program is included in the effectiveness and implementation studies and listed in the tables.</p> <p>Many of these are state, organization or University-specific resources which did not meet our inclusion criteria of US national resources. We have emphasized this in several places</p>
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			University of Colorado, Penn State College of Nursing, etc. f. Immersion courses such as those offered by Four Season or Harvard Medical School.	
16.	<b>Public Reviewer #5</b>	Results	<i>What Is the Effectiveness?</i> We agree with AHRQ’s overall observation that there is significant opportunity to grow the evidence base supporting palliative care training. That said, ELNEC has published extensively on the outcomes of its courses and the APRN palliative care externship has been shown to increase confidence in care delivery. For the latter, we suggest that this be considered for the list of “outcomes of interest” in Appendix A, Table 3.	Thank you – in a systematic review, the outcomes of interest are pre-specified before the review begins, in this case with a panel of palliative care experts who felt that “confidence in care delivery” should not be included and that we should instead include objective outcomes for these interventions that are associated with improved patient outcomes.



17.	<b>Public Reviewer #5</b>	Discussion	<p>Overall, this section clearly summarizes the extensive work done to identify and evaluate the literature supporting palliative care integration into ambulatory care settings for seriously ill, non-cancer patients. With that in mind:</p> <ul style="list-style-type: none"> <li>a. Responding to the comment “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” (pp. 62-63) – as a clinical practice guideline, the NCP was not designed to offer a single, standardized assessment. However, it references multiple tools in its appendices, and does indeed express an expectation that standardized identification systems for palliative care-eligible patients be integrated across care settings. Furthermore, it emphasizes the necessity of palliative care being an interdisciplinary approach to care, which did not appear to come through in most of the studies discussed.</li> <li>b. While we recognize that the study design required a focus on peer-reviewed literature, the result appeared to be an overemphasis on the role of advance care planning in palliative care. While this is an important component of palliative care interventions, other aspects such as expert communication and symptom management are equally critical. This is implicitly referenced in the subsection “Implications for Clinical Practice, Education, Research, or Health Policy,” but</li> </ul>	<ul style="list-style-type: none"> <li>a. Thank you, we have removed this sentence given your feedback and as it did not really fit in this paragraph on systematic reviews.</li> </ul> <p>Thank you for the comment that the NCP recommends interdisciplinary approaches to care – Some of the studies identified in the update search did have more of a focus on interdisciplinary care and we have emphasized the role of this (where it is feasible) in multiple places in the report.</p> <ul style="list-style-type: none"> <li>b. Thank you for this very important point. We have defined advance care planning more broadly in the introduction with the American College of Physicians’ conceptualization as serious illness communication throughout the course of illness – and have now come back to this in the discussion and emphasized the limitations of more limited advance care planning with Sean Morrison’s recent opinion piece as a reference.</li> </ul>
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			<p>could be made more explicit to support future research in these other domains.</p> <p>C. We appreciate that the development of this report began well before the rise of COVID-19 and the growing attention paid to health inequities, and that any research connecting palliative care to these issues is in early stages. However, these circumstances are highly relevant to palliative care delivery in ambulatory settings; therefore, it may be worthwhile to at least acknowledge them in this section. This would make the report timelier and, again, potentially catalyze the field to conduct more research in these domains.</p>	<p>c. Thank you, we have addressed COVID-19 and one of the new additional studies is a telehealth study.</p> <p>We greatly appreciate your input that none of these studies addressed health inequities, which is a major problem. We have added a statement in Discussion that none of these studies specifically addressed health equity or disparities, which is critical for future intervention research.</p>
18.	<b>Public Reviewer #5</b>	Appendices	While the Methods section states that the review focused on serious chronic illnesses other than cancer, several of the references in Appendix A included cancer-specific studies. It would be helpful to have more information on the inclusion/exclusion criteria.	The reviewer did not specify which references they were referring to. We have reviewed the references and clarified the inclusion/ exclusion criteria.



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19.	<b>Public Reviewer #6</b>	General	<p>The American Geriatrics Society (AGS) is writing to provide general feedback on AHRQ’s Draft Comparative Effectiveness Review on Integrating Palliative Care in Ambulatory Care of Non-Cancer Serious Chronic Illness. Our reviewers were supportive of the document and wished to highlight the need of education for patients, primary care providers, and consultants about palliative care and hospice in order to start palliative care conversations in outpatient settings. We also want to draw attention to the importance of discussing goals of care with patients/families as the first step; symptom management education is also necessary. We recommend that one way to change the palliative care outlook is incorporating it into curriculum for medical students and adding to all residency training; this way when healthcare professionals start providing independent patient care, they feel comfortable in bringing up the palliative care discussion.</p>	<p>Thank you for these comments. Within the scope of this project, we have highlighted that shared decision-making tools should also address symptom management. Education for trainees was outside the scope of this systematic review.</p>
20.	<b>Public Reviewer #6</b>	Discussion	<p>We also suggest moving discussion in the findings section about the increase in advance care planning (ACP) completion, patient satisfaction, and when patients and families want to engage in ACP to the beginning of the section, as this is important information to be highlighted.</p> <p>We recognize that this feedback may not be significantly impactful for the writing group, but we still wanted to share it with AHRQ in case any of it can be useful in highlighting the importance of palliative care and advance care planning education for both healthcare providers and patients.</p>	<p>Thank you, we have organized the findings in the Discussion by the key questions in the report – so the shared decision-making tool section results come after the results for triggers and patient/caregiver education.</p>