Supplemental materials for

Chyr LC, DeGroot L, Waldfogel JM, et al. Implementation and effectiveness of integrating palliative care into ambulatory care of noncancer serious chronic illness: mixed method review and meta-analysis. *Ann Fam Med*. 2022;20(1):77-83.

Supplemental Appendix 1. Methods

Study Selection (Tables 1a-1e)

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

The eligible studies had to meet all of the following criteria: 1) included adults 18 years of age and older with serious life threatening chronic illness or conditions (other than those only with cancer) and their caregivers, being seen in ambulatory settings; 2) included models for integrating palliative care or multimodal interventions in ambulatory settings; 3) reported outcomes of interest; 4) randomized controlled trial or non-randomized trial with a concurrent or historical comparison group (controlled trial or prospective cohort study) ; 5) published in English; and, 6) U.S.-based. The criterion for outcomes was applied at the full-text screening level only. An overview of the PICOTS inclusion and exclusion criteria is provided in Table 1a. We excluded non U.S.-based studies since this report was requested through a U.S. government process to evaluate evidence that would be relevant and improve quality of healthcare in the U.S.

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

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

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

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

	Inclusion	Exclusion
Population	Patients (≥18 years of age) with serious life-threatening chronic illness or conditions (other than those only with cancer) and their caregivers, being seen in ambulatory settings	• Studies with only cancer patients • Studies not focusing on ambulatory populations
Interventions	Models for integrating palliative care or multimodal interventions in ambulatory settings	Studies that report no intervention of interest

	Inclusion	Exclusion
Comparisons	Models for integrating palliative care or multimodal interventions in ambulatory settings Usual care	Studies that do not report the comparisons of interest*
Outcomes	Final (In hierarchy from patient-centered to health system. All patient- or caregiver-reported outcomes must be measured by a validated instrument.[1]) • 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 • Healthcare utilization (use and length of hospice care, hospitalizations, advance directive documentation) and costs and resource use (use of outpatient clinician services, including palliative care) Adverse effects • Medication side effects • Dropouts related to the intervention	• Studies that do not report the outcomes of interest
Type of Study	• Randomized controlled trials • Non-randomized studies with concurrent controls or historical controls ((controlled trials or prospective cohort studies)	• Articles published prior to the year 2000 • Non-English publications • Case reports or case series • Publications with no original data (e.g., editorials, letters, comments, reviews) • Full text not presented or unavailable, abstracts only
Setting and Timing	• Any timing • Ambulatory care settings • U.S.-based studies	• Hospital setting • Oncology setting • Emergency department • Nursing home and long-term care facilities

*Comparisons to other included interventions or to usual care.

Table 1b. Additional inclusion and exclusion criteria for qualitative, mixed-methods, and process evaluation studies

Criteria	Inclusion	Exclusion
Comparison	No comparison group needed	

Type of Study	• Systematic reviews of qualitative studies
	• Qualitative or mixed-methods studies: including studies that use a formal qualitative data collection method (e.g., interviews, focus groups, ethnography) and analysis methods (e.g., phenomenological, grounded theory, ethnographic and thematic analysis studies)
	• Process evaluation studies (type of implementation studies) including studies that address the following in results:
	  ○ Identifying/addressing barriers/facilitators
	  ○ Populations to target
	  ○ Mechanisms for success/failure
		• Qualitative studies: observation or artifact analysis
		• Process evaluation studies focusing only on research issues (e.g., fidelity, participant recruitment, intervention quality, participant engagement)

Sample Size		• Analysis of interest includes fewer than 10 participants

Table 1c: Literature Search Strategies on PubMed

Lead search string—population

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

1	Population string (see above)
2	coaching[tiab]
3	integrating[tiab]
4	"stepped care"[tiab]
5	"consultative care"[tiab]
6	"shared care"[tiab]
7	"Collaborative care"[tiab]
8	2 OR 3 OR 4 OR 5 OR 6 OR 7
9	Model[tiab]

10	Models[tiab]
11	9 OR 10
12	"chronic care"[tiab]
13	staffing[tiab]
14	Dignity[tiab]
15	"needs based"[tiab]
16	"clinical practice"[tiab]
17	"primary care"[tiab]
18	integrated[tiab]
19	12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18
20	11 and 19
21	8 OR 20
22	1 and 21
	Date limited (2000 to present)
	Not review
	English Language

Data Extraction and Risk of Bias Assessment

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

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

Risk of Bias Assessment of Quantitative Studies

Two reviewers independently assessed risk of bias for each quantitative study. For RCTs, we used the Cochrane Risk of Bias Tool, Version 2.[2] For non-randomized studies, we used the Cochrane Risk of Bias Assessment Tool for Non-Randomized Studies of Interventions (ROBINS-I tool).[3] Differences between reviewers were resolved through consensus.

Assessment of Quality of Qualitative Studies

For qualitative studies, we conducted quality assessment, as risk of bias is not relevant. We used the Joanna Briggs Institute Quality Appraisal Checklist[4, 5] to address elements specific to our key questions. Two reviewers independently assessed the methodological quality and resolved differences through consensus.

Data Synthesis and Analysis

We created a set of detailed evidence tables containing all information extracted from eligible studies (Supplemental Appendix 2). These tables include details and implementation of the intervention. We conducted meta-analyses for outcomes with at least three studies and the studies were sufficiently homogeneous with respect to key variables (population characteristics, study duration, and intervention). Randomized controlled trials and nonrandomized studies were analyzed separately. Statistical significance was set at a two-sided alpha of 0.05. Statistical heterogeneity among studies was evaluated using an I^2 statistic and anticipated statistical heterogeneity. For continuous outcomes, a standardized mean difference was calculated using a random-effects model with DerSimonian and Laird formula. All meta-analyses was conducted using STATA version 14 (College Station, TX). Two investigators combined and synthesized key findings from each qualitative study for the development of key themes related to the implementation of models from patients' perspectives.

Table 1d. Minimal clinically important differences and clinical cutoff scores for outcome assessment tools included in review

Domain/ Instrument	Scale	Minimal Clinically Important	Clinical Cutoff Scores

		Differences (MCIDs)	
Patient Satisfaction			
Group Health Association of America Consumer Satisfaction Survey[6]	20 - 100	None identified	None identified
Investigator constructed 5-point, Likert type scale[7]	0 - 5	None identified	None identified
Health-Related Quality of Life			
Kansas City Cardiomyopathy Questionnaire (KCCQ)[8, 9]	0 -100	4.3 (95%, CI 0.2 – 8.4)	
		5.3 (+/- 11) (deterioration) 5.7 (+/- 16) (improvement)	
McGill Quality of Life Questionnaire[9]	0 - 10	None identified	Good 7.9 (SD 1.3) Average (6.8 SD 1.2) Bad 5.3 (SD 1.1)
Multidimensional Quality of Life Scale – Cancer Version[10]	0 - 10	None identified	Low 8.7 (SD 0.8) High 6.6 (SD 1.2)
Functional Assessment of Chronic Illness Therapy – Palliative Care scale (FACIT-PAL)[11]	0-184	None identified	Karnofsky Performance ≤ 70 (cancer patients less able to carry out daily activities): 125.3 (SD 25.2) Karnofsky Performance ≥80 (cancer patients more able to carry out daily activities): 134.3 (SD 24)
Minnesota Living with HF Questionnaire (MLHFQ)[12]	0 - 105	19.14 (95% CI16.04 – 22.24)	
Quality of Life in Alzheimer's Disease (QoL-AD)[13, 14]	13 - 52	3.9	
		Half a standard deviation	
Bakas Caregiving Outcomes Scale[15]	15 - 105	None identified	
Overall Symptom Burden			
General Symptom Distress Scale[16]	0 - 10	None identified	
Edmonton Symptom Assessment Scale – Revised for Parkinson's Disease (ESAS – PD)[17]	0 -140	None identified	
Depression			
Patient Health Questionnaire – 8 (PHQ8)[18]	0-24	None identified	≥ 10 represents clinically

			significant depression
Patient Health Questionnaire – 9 (PHQ9)[19, 20]	0 - 27	5	
Edmonton Symptom Assessment Scale (ESAS)[21, 22]	0 -10	(improvement and deterioration)	
		1 Range: 0.8 to 2.2 (improvement) -0.8 to -2.3 (deterioration)	
Center for Epidemiological Studies Depression Scale[23-25]	0-60		Optimal cutoff score of 4
		There is no MCID for CESD	
		0.9	
Hospital Anxiety and Depression Scale (HADS)[26-28]	0 - 21	1.7 (Range 0.5 – 5.57)	
		1.6 (95% CI, 1.38 – 1.82) to 1.68 (95% CI, 1.48 – 1.87)	
		1.4 – 1.8	
Anxiety			
Generalized Anxiety Disorder – 7 (GAD-7)[29, 30]	0 - 21	3	
		4	
Edmonton Symptom Assessment Scale (ESAS)[21, 22]	0 - 10	1.1 (deterioration)	
		1	
Profile of Mood States (POMS)[31]	0-200	None identified	None identified
Hospital Anxiety and Depression Scale (HADS)[26-28]	0 - 21	1.7 (Range 0.81 – 5.21)	
		1.41 (95% CI, 1.18 – 1.63) to 1.57 (95% CI, 1.37 – 1.76)	
		1.1 - 2	
Psychological Well-Being			
Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being Scale (FACIT Sp-12)[32]	0 - 48	No reported MCID	
Spiritual Well-Being Scale[33]	20 - 120	None identified	None identified
Pain			
Composite from the Brief Pain Inventory called PEG: pain intensity (P), interference with enjoyment of life (E) and interference with general activity (G)[34]		None identified	None identified
Edmonton Symptom Assessment Scale (ESAS)[21, 22]	0 - 10	1.2 (improvement) 1.4 (deterioration)	
		1	
Numeric Rating Scale[35]	0 - 10	2	
Dyspnea			
Numeric Rating Scale[36]	0 - 10	0.5 - 2	
Edmonton Symptom Assessment Scale (ESAS)[22]	0 - 10	1	
University of California, San Diego Shortness of Breath Questionnaire[37, 38]	0 - 120	5 - 6	
		5	

Fatigue			
Patient-Reported Outcomes Measurement Information System PROMIS SF 8a[39]	8 - 40	2.5 - 4.5 (17 item short form) 3.0 - 5 (7 item short form)	
Edmonton Symptom Assessment Scale (ESAS)[21]	0 - 10	1.8 (deterioration)	
		1	
Caregiver Burden, Impact or Strain			
Zarit Burden Interview (ZBI – 12)[40]	0 - 48	None identified	
Montgomery Borgatta Caregiving Burden Scale – Objective Burden Subscale[41]	6 - 30	None identified	>23 (high score)
Montgomery Borgatta Caregiving Burden – Demand Burden Subscale[41]	4 - 20	None identified	>15 (high score)
Montgomery Borgatta Caregiving Burden – Stress Burden subscale[41]	4 - 20	None identified	>13.5 (high score)

Grading the Strength of the Body of Evidence

We graded the strength of evidence on critical outcomes for quantitative studies by using the grading scheme recommended by the Methods Guide for Conducting Comparative Effectiveness Reviews. We defined the critical outcomes as those most important for making decisions; we identified these a priori with input from the Technical Expert Panel. The critical outcomes included patient health-related quality of life, patient symptom burden, patient symptoms of depression, patient satisfaction, caregiver satisfaction, and advance directive documentation.

For each critical outcome, we assessed the number of studies, their study designs, the study limitations (i.e., risk of bias and overall methodological quality), the consistency of study results, the precision of any estimates of effect, the likelihood of reporting bias, and the overall findings across studies. Based on these assessments, we assigned a strength of evidence rating as being either high, moderate, or low, or insufficient evidence to estimate an effect or draw a conclusion. The team members reviewed the assigned grade and conflicts were resolved through consensus. We used the grading scheme recommended in the AHRQ Methods Guide for Effectiveness and Comparative Effectiveness Reviews (Methods Guide). We considered the following domains: study limitations, directness, consistency, and precision.[42]

Table 1e. Definitions of the grades of overall strength of evidence

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

Reference:

1. Aslakson RA, Dy SM, Wilson RF, et al. Patient- and Caregiver-Reported Assessment Tools for Palliative Care: Summary of the 2017 Agency for Healthcare Research and Quality Technical Brief. *J Pain Symptom Manage*. Dec 2017;54(6):961-972.e16. doi:10.1016/j.jpainsymman.2017.04.022
2. Sterne JAC, Savović J, Page MJ, et al. RoB 2: a revised tool for assessing risk of bias in randomised trials. *BMJ*. Aug 28 2019;366:l4898. doi:10.1136/bmj.l4898
3. Sterne JA, Hernán MA, Reeves BC, et al. ROBINS-I: a tool for assessing risk of bias in non-randomised studies of interventions. *BMJ*. 2016;355:i4919-i4919. doi:10.1136/bmj.i4919
4. Majid U, Vanstone M. Appraising Qualitative Research for Evidence Syntheses: A Compendium of Quality Appraisal Tools. *Qual Health Res*. Nov 2018;28(13):2115-2131. doi:10.1177/1049732318785358
5. Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. *Int J Evid Based Healthc*. Sep 2015;13(3):179-87. doi:10.1097/xeb.0000000000000062
6. Davies AR, Ware JE. *GHAA's consumer satisfaction survey and user's manual*. GHAA; 1991.
7. Engelhardt JB, McClive-Reed KP, Toseland RW, Smith TL, Larson DG, Tobin DR. Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: a randomized trial. *Am J Manag Care*. Feb 2006;12(2):93-100.
8. Butler J, Khan MS, Mori C, et al. Minimal clinically important difference in quality of life scores for patients with heart failure and reduced ejection fraction. *Eur J Heart Fail*. Jun 2020;22(6):999-1005. doi:10.1002/ejhf.1810
9. Spertus J, Peterson E, Conard MW, et al. Monitoring clinical changes in patients with heart failure: a comparison of methods. *Am Heart J*. Oct 2005;150(4):707-15. doi:10.1016/j.ahj.2004.12.010
10. Astrup GL, Hofsø K, Bjordal K, et al. Patient factors and quality of life outcomes differ among four subgroups of oncology patients based on symptom occurrence. *Acta Oncol*. Mar 2017;56(3):462-470. doi:10.1080/0284186x.2016.1273546
11. Lyons KD, Bakitas M, Hegel MT, Hanscom B, Hull J, Ahles TA. Reliability and validity of the Functional Assessment of Chronic Illness Therapy-Palliative care (FACIT-Pal) scale. *J Pain Symptom Manage*. Jan 2009;37(1):23-32. doi:10.1016/j.jpainsymman.2007.12.015
12. Gonzalez-Saenz de Tejada M, Bilbao A, Ansola L, et al. Responsiveness and minimal clinically important difference of the Minnesota living with heart failure questionnaire. *Health and Quality of Life Outcomes*. 2019/02/14 2019;17(1):36. doi:10.1186/s12955-019-1104-2
13. Holden SK, Koljack CE, Prizer LP, Sillau SH, Miyasaki JM, Kluger BM. Measuring quality of life in palliative care for Parkinson's disease: A clinimetric comparison. *Parkinsonism Relat Disord*. Aug 2019;65:172-177. doi:10.1016/j.parkreldis.2019.06.018
14. Naglie G, Hogan DB, Krahn M, et al. Predictors of patient self-ratings of quality of life in Alzheimer disease: cross-sectional results from the Canadian Alzheimer's Disease Quality of Life Study. *Am J Geriatr Psychiatry*. Oct 2011;19(10):881-90. doi:10.1097/JGP.0b013e3182006a67
15. Bakas T, Champion V, Perkins SM, Farran CJ, Williams LS. Psychometric testing of the revised 15-item Bakas Caregiving Outcomes Scale. *Nurs Res*. Sep-Oct 2006;55(5):346-55. doi:10.1097/00006199-200609000-00007
16. Badger TA, Segrin C, Meek P. Development and validation of an instrument for rapidly assessing symptoms: the general symptom distress scale. *J Pain Symptom Manage*. Mar 2011;41(3):535-48. doi:10.1016/j.jpainsymman.2010.06.011
17. Miyasaki JM, Long J, Mancini D, et al. Palliative care for advanced Parkinson disease: an interdisciplinary clinic and new scale, the ESAS-PD. *Parkinsonism Relat Disord*. Dec 2012;18 Suppl 3:S6-9. doi:10.1016/j.parkreldis.2012.06.013
18. Kroenke K, Strine TW, Spitzer RL, Williams JB, Berry JT, Mokdad AH. The PHQ-8 as a measure of current depression in the general population. *J Affect Disord*. Apr 2009;114(1-3):163-73. doi:10.1016/j.jad.2008.06.026
19. Löwe B, Unützer J, Callahan CM, Perkins AJ, Kroenke K. Monitoring depression treatment outcomes with the patient health questionnaire-9. *Med Care*. Dec 2004;42(12):1194-201. doi:10.1097/00005650-200412000-00006
20. Williams JW, Jr., Slubicki MN, Tweedy DS, Bradford DW, Trivedi RB, Baker D. VA Evidence-based Synthesis Program Reports. *Evidence Synthesis for Determining the Responsiveness of Depression Questionnaires and Optimal Treatment Duration for Antidepressant Medications*. Department of Veterans Affairs (US); 2009.
21. Bedard G, Zeng L, Zhang L, et al. Minimal clinically important differences in the Edmonton symptom assessment system in patients with advanced cancer. *J Pain Symptom Manage*. Aug 2013;46(2):192-200. doi:10.1016/j.jpainsymman.2012.07.022
22. Hui D, Shamieh O, Paiva CE, et al. Minimal clinically important differences in the Edmonton Symptom Assessment Scale in cancer patients: A prospective, multicenter study. *Cancer*. Sep 1 2015;121(17):3027-35. doi:10.1002/cncr.29437
23. Irwin M, Artin KH, Oxman MN. Screening for depression in the older adult: criterion validity of the 10-item Center for Epidemiological Studies Depression Scale (CES-D). *Arch Intern Med*. Aug 9-23 1999;159(15):1701-4. doi:10.1001/archinte.159.15.1701

24. Amtmann D, Kim J, Chung H, et al. Comparing CESD-10, PHQ-9, and PROMIS depression instruments in individuals with multiple sclerosis. *Rehabil Psychol*. May 2014;59(2):220-229. doi:10.1037/a0035919
25. Haase I, Winkeler M, Imgart H. [Anchor-based ascertaining of meaningful changes in depressive symptoms using the example of the German short form of the CES-D]. *Neuropsychiatr*. Jun 2016;30(2):82-91. Ankerbasierte Ermittlung klinisch relevanter Veränderung depressiver Symptomatik am Beispiel der Kurzform der CES-D. doi:10.1007/s40211-016-0184-z
26. Lemay KR, Tulloch HE, Pipe AL, Reed JL. Establishing the Minimal Clinically Important Difference for the Hospital Anxiety and Depression Scale in Patients With Cardiovascular Disease. *J Cardiopulm Rehabil Prev*. Nov 2019;39(6):E6-e11. doi:10.1097/hcr.0000000000000379
27. Puhan MA, Frey M, Büchi S, Schünemann HJ. The minimal important difference of the hospital anxiety and depression scale in patients with chronic obstructive pulmonary disease. *Health Qual Life Outcomes*. Jul 2 2008;6:46. doi:10.1186/1477-7525-6-46
28. Smid DE, Franssen FM, Houben-Wilke S, et al. Responsiveness and MCID Estimates for CAT, CCQ, and HADS in Patients With COPD Undergoing Pulmonary Rehabilitation: A Prospective Analysis. *J Am Med Dir Assoc*. Jan 2017;18(1):53-58. doi:10.1016/j.jamda.2016.08.002
29. Kroenke K, Baye F, Lourens SG. Comparative Responsiveness and Minimally Important Difference of Common Anxiety Measures. *Med Care*. Nov 2019;57(11):890-897. doi:10.1097/mlr.0000000000001185
30. Toussaint A, Hüsing P, Gumz A, et al. Sensitivity to change and minimal clinically important difference of the 7-item Generalized Anxiety Disorder Questionnaire (GAD-7). *J Affect Disord*. Mar 15 2020;265:395-401. doi:10.1016/j.jad.2020.01.032
31. Shacham S. A shortened version of the Profile of Mood States. *J Pers Assess*. Jun 1983;47(3):305-6. doi:10.1207/s15327752jpa4703_14
32. Munoz AR, Salsman JM, Stein KD, Cella D. Reference values of the Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being: a report from the American Cancer Society's studies of cancer survivors. *Cancer*. Jun 1 2015;121(11):1838-44. doi:10.1002/cncr.29286
33. Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy--Spiritual Well-being Scale (FACIT-Sp). *Ann Behav Med*. Winter 2002;24(1):49-58. doi:10.1207/s15324796abm2401_06
34. Krebs EE, Lorenz KA, Bair MJ, et al. Development and initial validation of the PEG, a three-item scale assessing pain intensity and interference. *J Gen Intern Med*. Jun 2009;24(6):733-8. doi:10.1007/s11606-009-0981-1
35. Dworkin RH, Turk DC, Wyrwich KW, et al. Interpreting the clinical importance of treatment outcomes in chronic pain clinical trials: IMMPACT recommendations. *J Pain*. Feb 2008;9(2):105-21. doi:10.1016/j.jpain.2007.09.005
36. Oxberry SG, Bland JM, Clark AL, Cleland JG, Johnson MJ. Minimally clinically important difference in chronic breathlessness: every little helps. *Am Heart J*. Aug 2012;164(2):229-35. doi:10.1016/j.ahj.2012.05.003
37. Horita N, Miyazawa N, Morita S, et al. Small, moderate, and large changes, and the minimum clinically important difference in the University of California, San Diego Shortness of Breath Questionnaire. *Copd*. Feb 2014;11(1):26-32. doi:10.3109/15412555.2013.808615
38. Kupferberg DH, Kaplan RM, Slymen DJ, Ries AL. Minimal clinically important difference for the UCSD Shortness of Breath Questionnaire. *J Cardiopulm Rehabil*. Nov-Dec 2005;25(6):370-7. doi:10.1097/00008483-200511000-00011
39. Yost KJ, Eton DT, Garcia SF, Cella D. Minimally important differences were estimated for six Patient-Reported Outcomes Measurement Information System-Cancer scales in advanced-stage cancer patients. *J Clin Epidemiol*. May 2011;64(5):507-16. doi:10.1016/j.jclinepi.2010.11.018
40. Kim OD, Cantave I, Schlesinger PK. Esophageal involvement by cutaneous T-cell lymphoma, mycosis fungoides type: diagnosis by endoscopic biopsy. *J Clin Gastroenterol*. Apr 1990;12(2):178-82. doi:10.1097/00004836-199004000-00013
41. Ampalam P, Gunturu S, Padma V. A comparative study of caregiver burden in psychiatric illness and chronic medical illness. *Indian J Psychiatry*. 2012;54(3):239-243. doi:10.4103/0019-5545.102423
42. Agency for Healthcare Research and Quality. *Methods Reference Guide for Effectiveness and Comparative Effectiveness Reviews*. 2007.

Supplemental Appendix 2. Results

Quantitative Studies (Tables 2a-2b)

Supplemental Table 2a. Characteristics of effectiveness studies assessing models for integrating palliative care

Author, Year	Study Characteristics	Intervention Description	Followup Duration
Shared Care Models			
Kluger, 2020[1]	n=210 patients and n=175 caregivers • RCT, multi-center, academic • Patients with Parkinson's disease and related disorders with moderate to high palliative care needs and their caregivers • Nonprofit funding	• Control: Neurologist and primary care practitioner provided standard care. • Intervention: Standard care plus outpatient integrated palliative care delivered by a neurologist, social worker, chaplain, nurse, and palliative medicine specialist. Palliative visits were every 3 months in-person or by telemedicine with as-needed followup phone calls. • Model type: Shared care.	12 months
Owens, 2013[2]	n=49 • Prospective cohort study, single center, academic • Integrated primary and palliative care clinic, patients with life-limiting illness • Funding source not reported	• Control: Usual care (not described). • Intervention: Primary Palliative Care Clinic: Integrated model of primary and palliative care led by nurse practitioner where consistent care was delivered by primary or palliative care clinician. • Model type: Shared care.	Varied, 2 weeks to 9 months
Rogers, 2017[3]	n=150 • RCT, single center, academic • Patients with advanced heart failure and high six-month mortality risk based on covariates measured at baseline • Government funding	• Control: Cardiology-directed team with focus on symptom relief and evidence-based therapies based on current guidelines. • Intervention: Palliative Care in Heart Failure: Usual care combined with an integrated care model of palliative care nurse practitioner supported by a palliative care physician managing physical symptoms, psychosocial and spiritual concerns, and advance care planning. • Model type: Shared care.	6 months

Author, Year	Study Characteristics	Intervention Description	Followup Duration
O'Riordan, 2019[4]	n=39 • RCT, single-center, academic • Patients with heart failure primary diagnosis or symptomatic heart failure as defined by New York Heart Association Class II-IV in current hospitalization or within prior 6 months • Nonprofit funding	• Control: Standard care was guideline-driven heart failure treatment. • Intervention: Intensive palliative care delivered by an interdisciplinary care team consisting of a nurse practitioner, physician, social worker, and chaplain. Consultation included prescribing medication, advance care planning, documentation completion, and provided needed psychosocial and spiritual support. First consultation occurred during the hospitalization with one-week in-person followup assessment combined with five monthly consultants (at least 2 in person or by teleconference. Model type: Shared care.	6 months
Consultative Care Models			
Bekelman, 2015[5]	n=392 • RCT, multi-center, Veterans Affairs • Primary care, patients with heart failure • Government funding	• Control: Continual care from primary care clinician and regular telehealth nurses if patient had previously enrolled, given information sheet during enrollment on self-management of heart failure, depression diagnosis provided to primary care clinician. • Intervention: Patient-Centered Disease Management (PCDM): heart failure disease management, home telemonitoring with patient self-support, and screening and management of depression. Collaborative care team consisted of a nurse coordinator (registered nurse), a primary care physician, a cardiologist, and a psychiatrist. • Model type: Consultative care.	12 months

Author, Year	Study Characteristics	Intervention Description	Followup Duration
Bekelman, 2018[6]	n=314 • RCT, multi-center, academic and Veterans Affairs health systems • Primary site not reported, patients with heart failure and reduced health status • Government funding	• Control: As needed, unstructured symptoms assessment and management by primary care physician or nurse practitioner; referral to social worker for psychosocial assessment and management, as needed; information sheets on self-care for heart failure. • Collaborative Care to Alleviate Symptom and Adjust to Illness (CASA): Clinician training/education combined with a palliative care model. Routine, structured symptom assessment and management by nurse (6 sessions, 1 to 2/month), routine, structured psychosocial assessment and management by social worker via telephone (6 sessions), collaborative care team including palliative care specialist and cardiologist provided care review and supervision. Nurse was trained in assisting with communication (1 hour), motivational interview (4 hours), and guidelines on symptoms (3 hours); social worker received training on psychosocial intervention training and supervision on followup visits (8 hours). • Model type: Consultative care.	6 months
Feely, 2016[7]	n=92 • Prospective cohort study, single center, academic • Outpatient hemodialysis unit, adult patients receiving hemodialysis • Funding source not reported	• Control: Usual care (not described). • Intervention: Integrated model of palliative care physician. consultations on a hemodialysis unit • Model type: Consultative care.	6 months
Rabow, 2004[8, 9]	n=90 • Controlled trial, single center, academic • Outpatient general medicine clinic, patients diagnosed with cancer, advanced COPD, or advanced CHF with life expectancy of 1 to 5 years but not ready for hospice • Non-profit funding	• Control: Usual primary care (not described). • Intervention: Comprehensive Care Team (CCT) patient/caregiver education combined with an integrated model of a social worker, nurse, chaplain, pharmacist, psychologist, art therapist, volunteer coordinator and three physicians addressing physical, emotional, and spiritual issues. • Model type: Consultative care.	12 months

Author, Year	Study Characteristics	Intervention Description	Followup Duration
Involving Care Coordinators/Social Workers In Care Delivery			
Engelhardt, 2006[10]	n=275 patients and n=168 caregivers • RCT, multi-center, Veterans Affairs (not specified if academic) • Patients with COPD or CHF who have one or more admissions to an intensive-care unit or two or more acute-admissions in the last 6 months • Non-profit funding	• Control: Usual care (not described). • Intervention: Advanced Illness Coordinated Care Program (AICCP): Six-session in-person intervention delivered by care coordinators (e.g., nurses, social workers – not specified) in the practices focused on helping patients develop questions and providing information to physicians, health literacy, care coordination, psychosocial issues, self-management, and end-of-life planning. • Model type: Involving Care Coordinators/Social Workers In Care Delivery.	6 months
O'Donnell, 2018[11]	n=50 • RCT, single-center, academic • Patients with heart failure who had recent hospitalization and are at high risk for poor prognosis • Private foundation funding	• Control: Usual care on advanced care planning and HRQOL. • Social worker-led palliative care intervention: Palliative care model integrating social worker into practice, guided by Serious Illness Conversation Guide, social worker led participants through structured goals-of-care discussion initially at the inpatient setting with subsequent telephone or clinic-based followup. • Model type: Involving Care Coordinators/Social Workers In Care Delivery.	6 months
Engelhardt, 2009[12]	n=532 • Controlled trial, multi-center, integrated managed care • Kaiser Permanente health system, patients with advanced stages of cancer, congestive heart filature, end-stage pulmonary disease, and end-stage renal disease and their caregivers • Nonprofit and Kaiser Permanente funding	• Control: Usual care (not described). • Intervention: Advanced Illness Coordinated Care Program (AICCP): Integrated model with six-session intervention delivered by social workers or health educators focused on nondirective health counseling, education, and care coordination in patients with advanced illness. • Model type: Involving Care Coordinators/Social Workers In Care Delivery.	Varied, 4 to 9 months

Author, Year	Study Characteristics	Intervention Description	Followup Duration
Dionne-Odom, 2020[13]	n=158 caregivers • RCT, multi-center, academic • Caregivers of patients with New York Heart Association Class III or IV heart failure and/or AHA/ACC stage C/D heart failure • Government funding	• Control: No intervention. • Intervention: Four weekly psychosocial and problem-solving support telephonic sessions lasting between 20 and 60 minutes facilitated by a trained nurse coach plus monthly followup. • Model type: Involving Care Coordinators/Social Workers In Care Delivery.	16 weeks

COPD = chronic obstructive pulmonary disease; CHF = congestive heart failure; CCT = comprehensive care team; AAICP = advanced illness coordinated care program; PCDM = patient-centered disease management; CASA = collaborative care to alleviate symptoms and adjust to illness; RCT = randomized controlled trial.

Table 2b. Summary of effectiveness findings for models for integrating palliative care and multimodal interventions by outcome

Outcome	Comparison	Number of Studies (N at Analysis)	Findings	Strength of Evidence
Patient-centered outcomes				
Patient satisfaction[4, 8-10]	Models for integrating palliative care vs. usual care	2 RCTs (n=216) 1 CT (n=90)	Models for integrating palliative care may have little to no effect on patient satisfaction compared with usual care.	Low
Patient HRQOL[1, 3-6, 8-11]	Models for integrating palliative care vs. usual care	6 RCTs (n=897) 2 CTs (n=90+)	Results were consistently not statistically or clinically different between groups. Models for integrating palliative care were not more effective than usual care for HRQOL.	Moderate
Overall symptom burden[1, 6]	Models for integrating palliative care vs usual care	2 RCTs (n=419)	Models for integrating palliative care may have little to no effect on overall symptom burden compared with usual care.	Low
Patient symptoms of depression[1-9, 11]	Models for integrating palliative care vs. usual care	6 RCTs (n=553+) 1 CT (n=90) 2 prospective cohort studies (n=86)	In a pooled analysis of three RCTs [11, 14, 15], we found no difference in symptoms of depression with a model for integrating palliative care compared with usual care (calculated standardized mean difference, -0.09; 95% CI, -0.35 to 0.17). Models for integrating palliative care were not more effective than usual care for symptoms of depression.	Moderate

Outcome	Comparison	Number of Studies (N at Analysis)	Findings	Strength of Evidence
Patient symptoms of anxiety[1-4, 6-9, 11]	Models for integrating palliative care vs. usual care	5 RCTs (n=561) 1 CT (n=90) 2 prospective cohort studies (n=87)	In a pooled analysis of three RCTs [11, 14, 15], we found no differences in anxiety for patients enrolled in a model for integrating palliative care compared with usual care (calculated standardized mean difference, 0.06; 95% CI, -0.2 to 0.32, I-squared=0%}. No statistically or clinically significant between-group differences. Models for integrating palliative care were not more effective than usual care for symptoms of anxiety.	Not graded
Patient psychological well-being[1, 3, 8, 9, 11, 12]	Models for integrating palliative care vs. usual care	3 RCTs (n=281) 2 CTs (n=90+)	Meta-analysis of the three RCTs showed no difference in psychological well-being compared with usual care (calculated standardized mean difference, 0.01; 95% CI, -0.39 to 0.41). Models for integrating palliative care were not more effective than usual care for symptoms of anxiety.	Not graded
Pain[2, 4, 6-9]	Models for integrating palliative care vs. usual care	2 RCTs (n=277) 1 CT (n=90) 2 prospective cohort studies (n=102)	None of the differences were clinically meaningful. Models for integrating palliative care were not more effective than usual care for pain.	Not graded
Dyspnea[2, 4, 6-9]	Models for integrating palliative care vs. usual care	2 RCTs (n=278) 1 CT (n=90) 2 prospective cohort studies (n=88)	Results were not clinically meaningful. Models for integrating palliative care were not more effective than usual care for dyspnea.	Not graded
Fatigue[2, 6, 7]	Models for integrating palliative care vs. usual care	1 RCT (n=248) 2 prospective cohort studies (n=88)	Primarily based on the larger RCT results, models for integrating palliative care may not be more effective than usual care for fatigue.	Not graded
Concordance between patient preferences and care received[11]	Models for integrating palliative care vs. usual care	1 RCT (n=31)	We were unable to draw conclusions.	Not graded

Outcome	Comparison	Number of Studies (N at Analysis)	Findings	Strength of Evidence
Caregiver-centered outcomes				
Caregiver HRQOL[13]	Models for integrating palliative care vs. usual care	1 RCT (n=82)	Models for integrating palliative care and usual care may have little to no effect on caregiver HRQOL compared with usual care.	Not graded
Caregiver symptoms of depression[1, 13]	Models for integrating palliative care vs. usual care	2 RCTs (n=228)	Differences were not clinically meaningful. Models for integrating palliative care were not more effective than usual care for symptoms of depression.	Not graded
Caregiver symptoms of anxiety[1, 13]	Models for integrating palliative care vs. usual care	2 RCTs (n=228)	Differences were not clinically meaningful. Models for integrating palliative care were not more effective than usual care for symptoms of anxiety.	Not graded
Caregiver psychological well-being[1]	Models for integrating palliative care vs. usual care	1 RCT (n=147)	There may be little to no difference in caregiver psychological well-being between models and usual care.	Not graded
Caregiver burden, impact, or strain[1, 13]	Models for integrating palliative care vs. usual care	2 RCTs (n=229)	There may be little to no difference in caregiver burden, impact, or strain between models and usual care.	Not graded
Healthcare utilization				
Use and length of hospice care[16, 17]	Multimodal interventions vs. usual care	1 CT (n=74)	We were unable to draw conclusions.	Not graded
Hospitalizations[5, 6, 8, 9, 12, 18]	Multimodal interventions vs. usual care Models for integrating palliative care vs. usual care	1 RCT (n=525) 2 RCT (n=698) 2 CT (n=493)	Multimodal: Results of one large RCT suggest that multimodal interventions may have little to no effect on hospitalizations compared with usual care. Models: Models for integrating palliative care were not more effective than usual care for hospitalizations.	Not graded

Outcome	Comparison	Number of Studies (N at Analysis)	Findings	Strength of Evidence
Advance directive documentation[1, 4, 7-12, 18]	Multimodal interventions vs. usual care Models for integrating palliative care vs. usual care	1 RCT (n=167) 4 RCTs (n=424) 2 CT (n=450) 1 prospective cohort studies (n=92)	Multimodal: Multimodal interventions may have little to no effect on advance directive documentation. Models: In a pooled analysis of four RCTs [10, 11, 14, 15], we found that patients enrolled in models integrating palliative care were 62.0% more likely to have a higher completion of AD documentation at 6 months (Relative Risk, 1.620 CI, 1.350 to 1.945) Based on the results of the meta-analysis and consistent results from additional studies, models for integrating palliative care are more effective than usual care for advance directive documentation.	Low Moderate
Cost and resource use[2, 8-10, 12, 19]	Multimodal interventions vs. usual care Models for integrating palliative care vs. usual care	1 CT (n=124) 3 CT (n=768) 1 prospective cohort study (n=49)	Multimodal: Based on results of one CT, multimodal interventions may have little to no effect on cost and resource use compared with usual care. Models: Studies varied widely in reporting and results, so we were unable to draw conclusions.	Not graded Not graded

RCT = randomized control trial; CT = controlled trial.

Qualitative Studies (Table 2c)

Table 2c. Characteristics of qualitative studies for models and multimodal interventions

Author, Year	Study and Participant Characteristics and Funding	Intervention Description
Shared Care Models		

Author, Year	Study and Participant Characteristics and Funding	Intervention Description
Bekelman, 2014[20]	n=17 patients • Multi-site, hospital and hospital outpatient clinic • Patients with advanced heart failure [New York Heart Association (NYHA) III/IV], hypertension, and COPD Government funding	• No control group. • Collaborative Care to Alleviate Symptom and Adjust to Illness (CASA): Clinician training/education combined with a palliative care model. Routine, structured symptom assessment and management by nurse (6 sessions, 1 to 2/month), routine, structured psychosocial assessment and management by social worker via telephone (6 sessions), collaborative care team including palliative care specialist and cardiologist provided care review and supervision. Nurse was trained in assisting with communication (1 hour), motivational interview (4 hours), and guidelines on symptoms (3 hours), social worker received training on psychosocial intervention training and supervision on followup visits (8 hours). • Model type: Shared Care Model.
Involving Care Coordinators/Social Workers In Care Delivery		
Goff, 2019[21]	n=Unclear number of participants • Multi-site, dialysis clinics • ESRD patients on dialysis and their surrogates Government funding	• Intervention: Communication intervention in which nephrologists and social workers communicated prognosis and advance care planning in face-to-face initial meetings with the patient, caregiver, and social worker, followed by monthly social work encounters for 18 months. • Model Type: Involving Care Coordinators/Social Workers in Care Delivery
Consultative Care Models		
Browyn-Long, 2014[22]	n=13 patients • Single-site, pulmonary specialty clinic • Patients with COPD Nonprofit and government funding	• Intervention: An advance practice nurse provided palliative care for people with COPD already receiving COPD-focused treatment. This nurse evaluated and treated participants' dyspnea, anxiety, and depression using usual pharmacologic and nonpharmacologic interventions appropriate for palliative care. Via weekly calls to participants, between appointments, the advance practice nurse monitored symptoms and tolerance of treatments, relaying this and treatment-related decision information to clinical co-investigators. • Model Type: Consultative Care Model
Rabow, 2003[23]	n=35 patients • Single-site, primary care • COPD, CHF, and cancer patients Nonprofit funding	• Intervention: Interdisciplinary palliative care team providing outpatient palliative care consultation, case management, psychological support, chaplaincy, caregiver training, medication review, and support groups. • Model Type: Consultative Care Model
Lakin, 2019[24]	n=17 primary care clinicians • Multi-site, primary care clinics • Primary care physicians, nurses, and social workers Nonprofit funding	• Intervention: The Serious Illness Care Program uses workflow innovations, clinician training, and clinical tools to improve serious illness communication. This methodology selects patients for serious illness conversations, which triggers mechanisms to remind clinicians to have such conversations, and electronic medical record documentation support. The program's core clinical tool, the Serious Illness Conversation Guide, provides a framework for best communication practices. • Multimodal intervention: Clinician training/ education plus triggers
Other, Non-Interventional Studies		
Nowels, 2016[25]	n=20 clinicians • Multi-site, primary care, • Primary care clinicians • Nonprofit funding	• No intervention evaluated. (Perceptions of palliative care in primary care)

Author, Year	Study and Participant Characteristics and Funding	Intervention Description
Scherer, 2018[26]	n=>57 key stakeholders • Single-site, outpatient kidney clinic • Nephrologists, dialysis nurses and social workers, office staff, hospitalists, administrators, vascular surgeons, cardiologists, other transplant team members • No funding	• No intervention evaluated. (Using participatory research to develop an outpatient integrated nephrology and palliative care program)
Bekelman, 2016[27]	n=17 clinicians and health system leaders • Multi-site, Veterans Health Administration, • Primary care, cardiology, ambulatory care, geriatrics, palliative care, mental health, and health system leaders within the Veterans Health Administration • Government funding	• No intervention evaluated. (Evaluating collaborative primary care and palliative care model)
Hobler, 2018[28]	n=48 patients • Single-site, cystic fibrosis clinic • Cystic fibrosis patients • Nonprofit funding	• No intervention evaluated. (Evaluating palliative care and advance care planning needs and clinicians' potential roles)
Bekelman, 2011[29]	n=52 (33 patients and 19 caregivers) • Multi-site, geriatrics and cardiology outpatient clinics • Patients with heart failure (NYHA II-IV) and their surrogates • Government and nonprofit funding	• No intervention evaluated. (Describing HF patients' and their surrogates' major concerns and needs and exploring whether, how, and when palliative care would be useful to them)

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

Reference:

1. Kluger BM, Miyasaki J, Katz M, et al. Comparison of Integrated Outpatient Palliative Care With Standard Care in Patients With Parkinson Disease and Related Disorders: A Randomized Clinical Trial. *JAMA Neurology*. 2020;77(5):551-560. doi:10.1001/jamaneurol.2019.4992
2. Owens D, Eby K, Burson S, Green M, McGoodwin W, Isaac M. Primary palliative care clinic pilot project demonstrates benefits of a nurse practitioner-directed clinic providing primary and palliative care. *J Am Acad Nurse Pract*. Jan 2012;24(1):52-8. doi:10.1111/j.1745-7599.2011.00664.x
3. Rogers JG, Patel CB, Mentz RJ, et al. Palliative Care in Heart Failure: The PAL-HF Randomized, Controlled Clinical Trial. *J Am Coll Cardiol*. Jul 18 2017;70(3):331-341. doi:10.1016/j.jacc.2017.05.030
4. O'Riordan DL, Rathfon MA, Joseph DM, et al. Feasibility of Implementing a Palliative Care Intervention for People with Heart Failure: Learnings from a Pilot Randomized Clinical Trial. *J Palliat Med*. Dec 2019;22(12):1583-1588. doi:10.1089/jpm.2018.0633
5. Bekelman DB, Plomondon ME, Carey EP, et al. Primary Results of the Patient-Centered Disease Management (PCDM) for Heart Failure Study: A Randomized Clinical Trial. *JAMA Intern Med*. May 2015;175(5):725-32. doi:10.1001/jamainternmed.2015.0315
6. Bekelman DB, Allen LA, McBryde CF, et al. Effect of a Collaborative Care Intervention vs Usual Care on Health Status of Patients With Chronic Heart Failure: The CASA Randomized Clinical Trial. *JAMA Intern Med*. Apr 1 2018;178(4):511-519. doi:10.1001/jamainternmed.2017.8667
7. Feely MA, Swetz KM, Zavaleta K, Thorsteinsdottir B, Albright RC, Williams AW. Reengineering Dialysis: The Role of Palliative Medicine. *Journal of Palliative Medicine*. 2016/06/01 2016;19(6):652-655. doi:10.1089/jpm.2015.0181
8. Rabow MW, Dibble SL, Pantilat SZ, McPhee SJ. The comprehensive care team: a controlled trial of outpatient palliative medicine consultation. *Arch Intern Med*. Jan 12 2004;164(1):83-91. doi:10.1001/archinte.164.1.83
9. Rabow MW, Petersen J, Schanche K, Dibble SL, McPhee SJ. The comprehensive care team: a description of a controlled trial of care at the beginning of the end of life. *J Palliat Med*. Jun 2003;6(3):489-99. doi:10.1089/109662103322144862
10. Engelhardt JB, McClive-Reed KP, Toseland RW, Smith TL, Larson DG, Tobin DR. Effects of a program for coordinated care of advanced illness on patients, surrogates, and healthcare costs: a randomized trial. *Am J Manag Care*. Feb 2006;12(2):93-100.
11. O'Donnell AE, Schaefer KG, Stevenson LW, et al. Social Worker-Aided Palliative Care Intervention in High-risk Patients With Heart Failure (SWAP-HF): A Pilot Randomized Clinical Trial. *JAMA Cardiol*. Jun 1 2018;3(6):516-519. doi:10.1001/jamacardio.2018.0589
12. Engelhardt JB, Rizzo VM, Della Penna RD, et al. Effectiveness of care coordination and health counseling in advancing illness. *Am J Manag Care*. Nov 2009;15(11):817-25.
13. Dionne-Odom JN, Ejem DB, Wells R, et al. Effects of a Telehealth Early Palliative Care Intervention for Family Caregivers of Persons With Advanced Heart Failure: The ENABLE CHF-PC Randomized Clinical Trial. *JAMA Netw Open*. Apr 1 2020;3(4):e202583. doi:10.1001/jamanetworkopen.2020.2583
14. O'Riordan DL, Rathfon MA, Joseph DM, et al. Feasibility of Implementing a Palliative CareIntervention for People with Heart Failure:Learnings from a Pilot Randomized Clinical Trial. *Journal of Palliative Medicine*. 2019;22doi:10.1089/jpm.2018.0633
15. Kluger BM, Miyasaki J, Katz M, et al. Comparison of Integrated Outpatient Palliative Care with Standard Care in Patients with Parkinson Disease and Related Disorders: a Randomized Clinical Trial. 2020;
16. Lakin JR, Robinson MG, Obermeyer Z, et al. Prioritizing Primary Care Patients for a Communication Intervention Using the “Surprise Question”: a Prospective Cohort Study. *Journal of General Internal Medicine*. 2019/08/01 2019;34(8):1467-1474. doi:10.1007/s11606-019-05094-4
17. Lakin JR, Koritsanszky LA, Cunningham R, et al. A Systematic Intervention To Improve Serious Illness Communication In Primary Care. *Health Aff (Millwood)*. Jul 1 2017;36(7):1258-1264. doi:10.1377/hlthaff.2017.0219
18. Goldstein NE, Mather H, McKendrick K, et al. Improving Communication in Heart Failure Patient Care. *J Am Coll Cardiol*. Oct 1 2019;74(13):1682-1692. doi:10.1016/j.jacc.2019.07.058
19. Lakin JR, Neal BJ, Maloney FL, et al. A systematic intervention to improve serious illness communication in primary care: Effect on expenses at the end of life. *Healthc (Amst)*. Jun 2020;8(2):100431. doi:10.1016/j.hjdsi.2020.100431
20. Bekelman DB, Hooker S, Nowels CT, et al. Feasibility and acceptability of a collaborative care intervention to improve symptoms and quality of life in chronic heart failure: mixed methods pilot trial. *J Palliat Med*. Feb 2014;17(2):145-51. doi:10.1089/jpm.2013.0143
21. Goff SL, Unruh ML, Klingensmith J, et al. Advance care planning with patients on hemodialysis: an implementation study. *BMC Palliat Care*. Jul 26 2019;18(1):64. doi:10.1186/s12904-019-0437-2
22. Long MB, Bekelman DB, Make B. Improving Quality of Life in Chronic Obstructive Pulmonary Disease by Integrating Palliative Approaches to Dyspnea, Anxiety, and Depression. *Journal of Hospice & Palliative Nursing*. 2014;16(8):514-520. doi:10.1097/njh.0000000000000111

23. Rabow MW, Schanche K, Petersen J, Dibble SL, McPhee SJ. Patient perceptions of an outpatient palliative care intervention: "It had been on my mind before, but I did not know how to start talking about death...". *J Pain Symptom Manage*. Nov 2003;26(5):1010-5. doi:10.1016/j.jpainsymman.2003.03.002
24. Lakin JR, Benotti E, Paladino J, Henrich N, Sanders J. Interprofessional Work in Serious Illness Communication in Primary Care: A Qualitative Study. *J Palliat Med*. Jul 2019;22(7):751-763. doi:10.1089/jpm.2018.0471
25. Nowels D, Jones J, Nowels CT, Matlock D. Perspectives of Primary Care Providers Toward Palliative Care for Their Patients. *The Journal of the American Board of Family Medicine*. 2016;29(6):748-758. doi:10.3122/jabfm.2016.06.160054
26. Scherer JS, Wright R, Blaum CS, Wall SP. Building an Outpatient Kidney Palliative Care Clinical Program. *J Pain Symptom Manage*. Jan 2018;55(1):108-116.e2. doi:10.1016/j.jpainsymman.2017.08.005
27. Bekelman DB, Rabin BA, Nowels CT, et al. Barriers and Facilitators to Scaling Up Outpatient Palliative Care. *J Palliat Med*. Apr 2016;19(4):456-9. doi:10.1089/jpm.2015.0280
28. Hobler MR, Engelberg RA, Curtis JR, et al. Exploring Opportunities for Primary Outpatient Palliative Care for Adults with Cystic Fibrosis: A Mixed-Methods Study of Patients' Needs. *J Palliat Med*. Apr 2018;21(4):513-521. doi:10.1089/jpm.2017.0259
29. Bekelman DB, Nowels CT, Retrum JH, et al. Giving voice to patients' and family caregivers' needs in chronic heart failure: implications for palliative care programs. *J Palliat Med*. Dec 2011;14(12):1317-24. doi:10.1089/jpm.2011.0179