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Review Article

Interventions Guiding Advance Care Planning Conversations: A Systematic Review

Jurrianne C. Fahner MD [a,*], Alexandra J.M. Beunders MD [a],
Agnes van der Heide MD, PhD [b], Judith A.C. Rietjens MSc, PhD [b],
Maaike M. Vanderschuren MD [a], Johannes J.M. van Delden MD, PhD [a],
Marijke C. Kars RN, PhD [a]

[a] Julius Center for Health Sciences and Primary Care, University Medical Center Utrecht, Utrecht, the Netherlands
[b] Department of Public Health, Erasmus Medical Center, Rotterdam, the Netherlands

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ABSTRACT

Background: Advance care planning (ACP) is a communicative process of defining preferences for future medical care. Conversation guides support professionals to conduct ACP conversations, yet insight into essential components is limited.

Objectives: To evaluate the content, rationale, and empirical evidence on the effect of ACP interventions based on conversation guides.

Methods: MEDLINE, Embase, PsycINFO, and CINAHL were searched from January 1, 1998, to February 23, 2018, to identify peer-reviewed articles describing or evaluating ACP interventions based on scripted conversation guides. A thematic analysis of the guides was performed. Data on intervention characteristics, underlying rationale, and empirical evidence were extracted by 2 authors independently using a predesigned form. Assessment of risk of bias and quality of reporting was performed using Cochrane tools and COREQ, respectively.

Results: Eighty-two articles reporting on 34 unique interventions met the inclusion criteria. Analysis of the conversation guides revealed a framework for ACP conversations consisting of 4 phases: preparation, initiation, exploration, and action. Exploration of patient's perspectives on illness, living well, end-of-life (EOL) issues, and decision making formed the core part of the guides. Their design was often expert-based, without an underlying theoretical background. Empirical evidence on the effect of the interventions was based on heterogeneous outcome measures. Dyad congruence and preference documentation rates increased among intervention subjects in most studies. The studies showed varying effects on knowledge of ACP, decisional conflict, quality of communication, and preferences-concordant care. Qualitative research showed that participants appreciate the importance and benefits of ACP conversations, yet perceive them as difficult and emotional.

Conclusion: ACP conversation guides address a diversity of themes regarding illness, EOL issues, and decision making. There is a focus on the exploration of patient's perspectives and preferences. Evidence on the translation of explorative information into specific treatment preferences and consequences for care as provided is limited.

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* Address correspondence to Jurrianne C. Fahner, MD, Julius Center for Health Sciences and Primary Care, Medical Humanities, University Medical Center Utrecht, Internal mail no Str. 6.131, PO Box 85500, 3508 GA Utrecht, the Netherlands.
E-mail address: j.c.fahner@umcutrecht.nl (J.C. Fahner).

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Especially in long-term care, the exploration of patients' perspectives on their illness and future medical needs is essential to provide high-quality medical care.[1] Advance care planning (ACP) is known as a strategy to communicate about preferences for future medical care. ACP is defined by an international taskforce as follows: "ACP enables individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and healthcare providers, and to record and review these preferences if appropriate."[2] When an individual's health situation worsens, ACP can become more targeted.[2] Evidence for the effects of ACP on completion of advance directives, improved patient-family concordance regarding preferences for medical care, and increased congruence between preferences for care and actual received care is growing.[3–5] Unfortunately, barriers such as lack of knowledge about ACP and lack of conversation skills among professionals remain.[6,7] Several interventions have been developed to support health care professionals to discuss goals and preferences for future medical care in daily practice. These interventions support professionals by providing guidance to the structure and content of ACP conversations through a conversation guide.[8] To our knowledge, no systematic review has been performed to provide an overview of the content of ACP conversation guides, their rationale, and effectiveness so far. Such an overview would be helpful to understand how the concept of ACP is translated into actual conversations and practices and could support health care professionals to conduct ACP conversations themselves. Therefore, this review aims to (1) provide a narrative synthesis of the characteristics and theoretical background of interventions that incorporate an ACP conversation guide, (2) provide an analysis of the structure and content of those conversation guides, and (3) summarize empirical evidence about the feasibility and effects of the interventions.

Methods

Data Sources and Searches

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist was used to structure the review process.[9] A structured computerized literature search was performed in 4 databases: MEDLINE, Embase, PsycINFO, and CINAHL. The search strategy included terms describing the following domains: *advance care planning*, *intervention*, and *communication* (Table 1). Two reviewers (J.F., M.V.) independently screened all abstracts to select relevant papers. Disagreements were resolved by discussion. Reference lists of selected studies were hand-searched for additional relevant papers (J.F. and K.P.).

Study Selection

Studies that were published in English in peer-reviewed journals between January 1, 1998, and February 23, 2018, describing a structured approach of ACP conversations by providing a conversation guide with verbal examples for health care professionals, were considered eligible. If the content of the conversation guide was not described in detail, more information was requested by contacting the corresponding author. Full texts of potentially eligible studies were assessed independently by 2 reviewers (J.F., M.V.). Disagreements were resolved by discussion.

Data Extraction and Quality Assessment

Data extraction was performed by 2 reviewers (J.F., A.B.) using a predesigned form. Characteristics of the interventions were extracted based on the Taxonomy of Schulz.[10] Any theoretical background and data on feasibility and effectiveness were extracted. Two reviewers (J.F., A.B.) performed a risk of bias assessment on the included quantitative studies. For randomized controlled trials and non-randomized controlled trials the Cochrane Bias Tool was used, evaluating random sequence generation, allocation concealment, blinding of participants, blinding of outcome assessment, incomplete outcome data, and selective reporting.[11] A score of 1 was assigned when the criterion had been met, indicating a low risk of bias, a score of 0 when the criterion had not been met, and a question mark when the information for rating the criterion was lacking. The rating resulted in a total score ranging from 0 to 6. Observational studies were assessed in a similar

Table 1
Search Strategy for all Databases

Search Strategy for MEDLINE (Ovid MEDLINE Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE Daily and Ovid MEDLINE [1946 to Present])
exp "advance care planning"/OR ((advance adj preferences) or (advance* adj3 planning) or (advance* adj2 directive*) or living will* or life-limiting or ("end-of-life" adj (care or plan* or decision*)) or "terminal care" or (future care adj3 planning)).'ti,ab,kf'.
AND
Communication/or goals/OR (intervention or conversation* or facilitate or approach or tool or document* or discussion* or goal* or program* or "decision aid" or communication).'ti,ab,kf'.
Search strategy for Embase (embase.com)
’living will’/exp OR ′terminal care’/exp OR (advance NEAR/1 preferences):ti,ab,de OR (advance* NEAR/3 planning):ti,ab,de OR (advance* NEAR/2 directive*):ti,ab,de OR (living NEAR/1 will*):ti,ab,de OR ′life limiting’:ti,ab,de OR (’end-of-life’ NEAR/1 (care OR plan* OR decision*)):ti,ab,de OR ′terminal care’:ti,ab,de OR (’future care’ NEAR/3 planning):ti,ab,de OR (’palliative therapy’/exp AND ′patient care planning’/exp)
AND
(’interpersonal communication’/exp OR ′goal attainment’/exp OR intervention:ti,ab,de OR conversation*:ti,ab,de OR facilitate:ti,ab,de OR approach:ti,ab,de OR tool:ti,ab,de OR document*:ti,ab,de OR discussion*:ti,ab,de OR goal*:ti,ab,de OR program*:ti,ab,de OR ′decision aid’:ti,ab,de) NOT (’conference abstract’/it OR ′conference paper’/it OR ′conference review’/it OR ′review’/it) AND [embase]/lim
Search strategy for PsycINFO (Ovid, PsycINFO [1806 to February Week 3 2018])
exp Treatment Planning/and exp Palliative Care/or exp Palliative Care/and exp Decision Making/or ((advance adj preferences) or (advance* adj3 planning) or (advance* adj2 directive*) or living will* or life-limiting or ("end-of-life" adj (care or plan* or decision*)) or "terminal care" or (future care adj3 planning)).ti,ab,id. or 'exp Advance Directives/'
AND
exp COMMUNICATION/OR exp GOALS/or (intervention or conversation* or facilitate or approach or tool or document* or discussion* or goal* or program* or "decision aid" or communication).'ti,ab,id'.
Search strategy for CINAHL (Ebscohost, CINAHL Plus with Full Text)
'MH ″advance care planning" or (TI((advance N1 preferences) or (advance* N3 planning) or (advance* N2 directive*) or (living N1 will*) or life-limiting or ("end-of-life" N1 (care or plan*)) or "terminal care" or ("future care" N3 planning))) or (AB((advance N1 preferences) or (advance* N3 planning) or (advance* N2 directive*) or (living N1 will*) or life-limiting or ("end-of-life" N1 (care or plan*)) or "terminal care" or ("future care" N3 planning)))'
AND
'(MH ″Goals and Objectives+") OR (MH ″Goal-Setting") OR (MH ″Goal Attainment") or AB(intervention or conversation* or facilitate or approach or tool or document* or discussion* or goal or program* or "decision aid" or communication) or TI(intervention or conversation* or facilitate or approach or tool or document* or discussion* or goal or program* or "decision aid" or communication) or MH ″communication+"'
Search date: February 23, 2018

way with the use of an adapted version of the Cochrane Bias tool (Appendix Table A1) assessing 7 categories: selection study population, comparability of study groups, standardization intervention protocol, standardization outcome measurements, missing data, confounders, and selective outcome reporting.[11] The criteria were rated as described above, and this resulted in a total score ranging from 0 to 7. The assessment tools do not include a cutoff point for categorizing the studies based on their risk of bias. Therefore, median scores with ranges are presented. The quality of reporting was assessed for qualitative studies using the COmprehensive consolidated criteria for REporting Qualitative research (COREQ).[12] The checklist evaluates a total of 32 criteria on 3 categories: (1) research team and reflexivity, (2) study design, and (3) analysis and findings. A score of 1 was assigned when the criterion had been properly described, a score of 0 when it was not described, and a score of 0.5 when the description was incomplete. The rating resulted in a total score ranging from 0 to 32. Mixed-methods studies were assessed both for risk of bias and quality of reporting. Disagreements were resolved by discussion. In line with the explorative nature of this review, the quality of selected studies did not affect inclusion.[13]

Data Synthesis and Analysis

We analyzed the data to provide a narrative synthesis of the characteristics, conceptual background, and feasibility and effectiveness of the interventions.[14] The content of the conversation guides was thematically analyzed using NVivo 10.[15] Open coding of the first 5 guides and categorization of codes resulted in an initial conceptual framework of the structure, themes, and language of the conversation guides. Subsequently, guides were coded using these initial concepts, and new concepts were created when deemed necessary (J.F. and M.K.). The concepts were clustered into themes. Sample statements were selected from the conversation guides to illustrate the themes.

Results

The search yielded 15,745 unique hits. Eighty-two articles met the inclusion criteria (Figure 1) reporting on 34 unique ACP interventions. Sixty-one articles presented empirical data about 27 interventions.[16–76] The remaining articles presented a description of the intervention or a study protocol.[7,77–96]

Risk of Bias and Quality of Reporting

A detailed overview of the risk of bias assessment and quality of reporting assessment underlying the total scores is presented in the Appendix Tables A2 to A6. The total scores for each study are presented in the evidences tables, which are described below. For randomized controlled trials (n = 21) and nonrandomized controlled

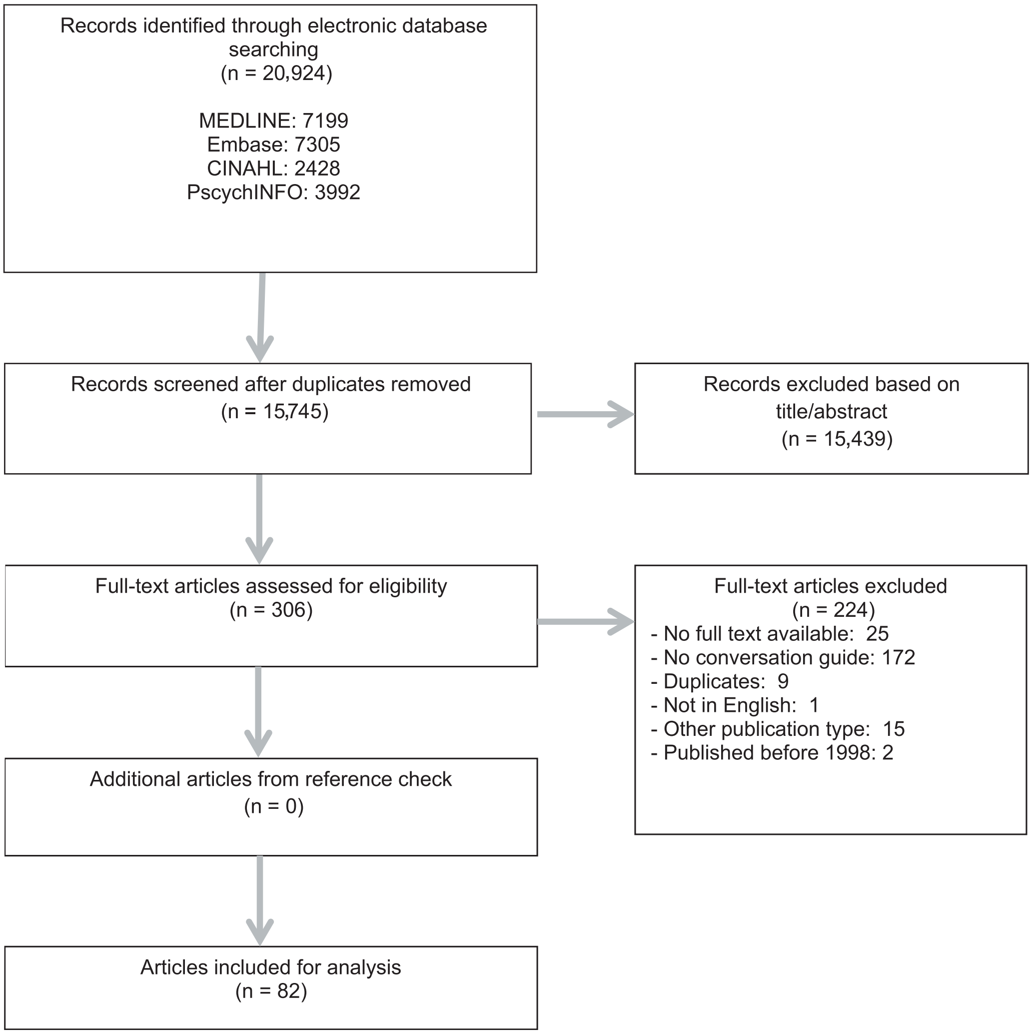

Fig. 1. PRISMA flow diagram of literature review process.

Table 2
Overview Characteristics and Available Evidence

Intervention (Country) Accessibility	Characteristics Intervention					Included Publications		
	Mode, Schedule, and Setting	Target Population	Interventionist	Scripting and Materials	Treatment Implementation	Description Intervention	Feasibility Outcomes	Effect Outcomes
I1. ACP for adults with congenital/pediatric heart disease (USA) Guide included in article[16]	Face-to-face conversation at heart failure and transplant clinic	Patients aged ≥18 y with congenital/pediatric heart disease	Transplant and cardiomyopathy coordinators	Exact scripted conversation guide Patient information folders Previsit provision of Voicing My Choices Documentation format in EHR	Documented AD			Edwards 2018[16]
I2. ACP by general practitioners (Belgium) Guide available from author[7]	Face-to-face conversation in general practice	Patients at risk of deteriorating or dying	General practitioner (2-h training program)	Exact scripted conversation guide Educational materials for GPs Register eligible patients Educational booklet patients Documentation template	Template for documentation of the discussion GPs encourage patient to share document with other health care providers	DeVlemick 2016[7]		
I3. ACP in COPD (Canada) Guide as appendix[17]	Double session face-to-face conversation at home	Patients with advanced COPD and their informal care givers	Facilitator (trained)	Conversation guide with question examples Information booklet for patients	Completion of advance directive		Simpson 2011[17] Simpson 2012[18]	Simpson 2011[17] Simpson 2012[18]
I4. ACP in early dementia (UK) Guide as appendix[19]	Face-to-face conversation at memory service clinic	Patients with early (mild) dementia and their carers	Senior nurse and clinical psychologist	Exact scripted conversation guide, also used for documentation Training package for staff	Authors emphasize need to make ACP documentation available to other health care providers		Poppe 2013[19]	Poppe 2013[19]
I5. ACP in geriatric patients (Norway) Guide included in article[20]	Single bedside face-to-face conversation at geriatric ward	Patients admitted to geriatric hospital ward	Senior consultant of geriatric department	Exact scripted conversation guide	NS		Friis 2015[20]	Friis 2015[20]
I6. ACP in patients with Chronic Kidney disease (Canada) Guide as appendix[77]	Face-to-face conversation included in university-based renal program	Adults with end-stage renal disease and surrogates	Social workers and nephrologists, preferably trained	Conversation guide with question examples	Documentation of ACP process in dialysis medical record	Davison 2007[77] Davison 2012[76]		
I7. ACP for patients with inoperable lung cancer* (UK) Guide partial available in article[21]	Face-to-face conversation at outpatient clinic	Patients with inoperable lung cancer	Lung cancer nurses	Exact scripted conversation guide Letter to record discussion Checklist to clarify content of ACP record with patients	GP clinic letter to record ACP discussion		Horne 2006[21]	Horne 2006[21]
I8. ACP Group Medical Visit (USA) Guide included in article[22]	Two group sessions of 2 h each, 1 mo apart at Senior Clinic	Geriatric patients (age >65 y) receiving care at primary care clinic	Geriatrician and social worker	Conversation guide with question examples Educational materials (handout, video, AD template)	Update AD or medical orders as needed Communication preferences to primary care provider		Lum 2016[22] Lum 2017[23]	Lum 2016[22] Lum 2017[23]

I9. Advance Directive in Two Questions (USA) Guide included in article[78]	Face-to-face conversation in any health care setting	Any patient	Any health care professional	Two scripted questions as base for discussion	Preferences described in short document, copies for patient, chart and palliative care team	Mahon 2012[78]		
I10. Communication about EOL care among patients with COPD (USA) Guide partial available in article and from author[24]	Face-to-face conversation based on patient-specific feedback form generated by a patient-reported computerized process at regular visits at outpatient clinic	Patients with COPD	Clinicians	Clinician feedback report with patient-specific discussion topics and suggested scripts	Feedback form was send to clinician and patient		Au 2012[24]	Au 2012[24] Reinke 2017[25]
I11. Communication in life-limiting illness (USA) Guide included in article[80]	Single or multiple face-to-face conversation preferable in outpatient setting, but can be in hospital as well	Patients with life-limiting illness	Clinicians	Conversation guide with examples of questions	Authors emphasize need to record ACP conversations in the patient chart and to include a copy of any completed documents	Pearce 2016[80]		
I12. End-of-Life Preferences Interview (Italy) Guide as appendix[26]	Single- or multiple-session face-to-face conversation in palliative (home) care centers	Patients in palliative care[23] Advanced cancer patients in palliative care[24]	Physicians palliative care centers (1 d of training)[24]	Exact scripted conversation guide Manual for interventionist	Documentation based on interview format		Borreani 2008[26] Borreani 2012[27]	-
I13. Family/Adolescents – Centered (FACE) ACP intervention[*] (USA) Copyrighted: guide based on I25, guide partial available in article[29]	Three-session face-to-face conversation, 1 wk apart at outpatient clinic	Adolescents with cancer and their surrogate[27,32,33] Adolescents with HIV/AIDS and their surrogate[28–31,36]	A certified Respecting Choices facilitator	Exact scripted conversation guide Readiness survey AD: Five Wishes Information brochure about ACP for participants	Completion of AD	Dallas 2012[81,†] Kimmel 2015[82,†] Curtin 2017[83,†]	Jacobs 2015[28] Lyon 2009[29] Lyon 2013[33] Dallas 2016[37] Lyon 2017[35] Lyon 2017[36]	Lyon 2009[29] Lyon 2009[30] Lyon 2010[31] Lyon 2011[32] Lyon 2013[33] Lyon 2014[34] Dallas 2016[37] Lyon 2017[35] Lyon 2017[36]
I14. Goals of Care Communication Guide (USA) Guide included in article[38]	Face-to-face conversation in outpatient setting or at home	Seriously ill patients	Nurse and social worker	Exact scripted conversation guide and documentation form	Completion of written document		Bekelman 2017[38]	
I15. Heart Failure End of Life Discussion intervention (USA) Guide included in article[84]	Face-to-face conversation	African Americans with heart failure	Nurse	Conversation guide with question examples Trajectory graph Conversation Ready pamphlet Preferences form	Completion of written document	Piamjariyakul 2017[84]		
I16. Kitchen Table Discussion (USA) Guide included in article[85]	Single or multiple session face-to-face conversation at home	Serious ill patients Patients with life-limiting illness receiving home care[39]	Home care and hospice nurses[38] Social worker[84]	Conversation guide with examples Guide used as assessment form for documentation	Assessment form in medical record and send to home care nurse and attending physician	Norlander 2000[85]	Ratner 2001[39]	Ratner 2001[39]

(*continued on next page*)

Table 2 (*continued*)

Intervention (Country) Accessibility	Characteristics Intervention					Included Publications		
	Mode, Schedule, and Setting	Target Population	Interventionist	Scripting and Materials	Treatment Implementation	Description Intervention	Feasibility Outcomes	Effect Outcomes
I17. Let me Talk (China) Guide available from author[40]	Single or multiple session face-to-face conversation and a family conference at a nursing home	Frail but competent nursing home residents	Nurse facilitator	Exact scripted conversation guide Information leaflet for residents Template for personal booklet	Personal booklet summarizing life stories and preferences for care		Chan 2010[40]	Chan 2010[40]
I18. Living Well Interview (USA) Guide included in article[41]	Single session face-to-face conversation at chemotherapy ward	Patients with recent diagnosis of life-limiting disease/ terminally ill patients	Oncology nurse (well-trained)	Exact scripted conversation guide			Schwartz 2003[41]	
I19. Motivational Stage-Tailored Intervention to ACP (USA) Guide available from author[42]	Single session face-to-face conversation at supportive housing facility	Low-income older adults living in a supportive housing facility	Social work graduate research assistant (45 h of training)	Conversation guide with question examples California AD form Training manual	Completion of AD form		Ko 2016[42]	Ko 2016[42]
I20. Palliative Care Program (China) Guide as appendix[43]	Weekly face-to-face conversations at home, part of an 8-wk program	Home care patients with life-limiting disease	Trained nurse facilitators/home care providers (2 days of training)	Conversation guide with question examples Educational materials	Completion of DNR order		Chan 2014[43]	Chan 2014[43]
I21. Patient Preferences About Serious Illness Instrument (PASI) (USA) Guide available from author[44]	Single or multiple session face-to-face conversation in hospital, outpatient or acute care setting	Seriously ill patients	Health care practitioners	Exact scripted conversation guide	The interview instrument should be used in conjunction with an AD		Whitehead 2016[44]	
I22. Patient Navigator Intervention to improve palliative care (USA) Guide available from author[45]	Five or more (if needed) sessions of face-to-face conversation in setting as preferred by patient (home, outpatient clinic, or during hospitalization)	Latino adults with life-limiting illness	Patient navigator (1-mo-long intensive training)	Exact scripted conversation guide Packet of linguistically matched materials on palliative care AD form	Completion of AD Documentation of pain management		Fischer 2015[45]	Fischer 2015[45]
I23. Physician's Guide to Talking About End-of-Life Care (USA) Guide included in article[95]	Face-to-face conversation, preferably in more than one session	Seriously ill patients	Physician	Conversation guide with question examples		Balaban 2000[96]		
I24. Preserving Identity and Planning for Advance Care (PIPAC) (USA) Guide available from author[46]	Four sessions, 1 wk apart, face-to-face conversation at home (including assisted living facilities and nursing homes)	Individuals with early or mild-stage dementia	Trained assessors with social worker or psychology background	Exact scripted conversation guide Participant notebook Checklist Document contributions participants Materials for a reminiscence product	A tangible reminiscence product Consideration of completing a legal document		Hilgeman 2014[46]	Hilgeman 2014[46]

I25. Respecting Choices[*] (USA)[‡] Copyrighted: guide partially available in article[86] Guide available from author[89]	Single session face-to-face conversation at diverse settings, mostly outpatient facilities	Seriously ill patients and their surrogate CHF[47,52,53,89] ESRD[47,50,52,53] High-risk open heart surgery[47] Ambulatory geriatric patients[54] Patients from cardiothoracic surgery clinic[55] Nursing home patients[51,62,90] Patients newly diagnosed with advanced lung cancer[56,57] Frail elderly patients with multiple comorbidities/advanced disease[48] Residents of assisted living facilities with limited life expectancy[60] Patients with advanced lung or colorectal cancer[87,88] Cancer patients[58,59]	Trained facilitator (Respecting Choices training)	Exact scripted conversation guide Training program for facilitators Information for patients Checklist for interview	Completion of AD	Briggs 2004[86] Korfhage 2015[87,†] Rietjens 2016[87,†] Malhotra 2016[89,†] In der Schmitten 2011[90,†]	Briggs 2004[47] Boettcher 2014[48] Hall 2014[49] Song 2010[50] In der Schmitten 2014[51] Kirchhoff 2010[52] Schwartz 2002[54] Song 2005[55] Robinson 2011[56] Robinson 2012[57] Niranjan 2018[58] Rocque 2017[59]	Boettcher 2014[48] Hall 2014[49] Hammes 2010[60] Pecanac 2016[61] Song 2010[50] In der Schmitten 2014[51] Kirchhoff 2010[52] Kirchhoff 2012[53] Schwartz 2002[54] Song 2005[55] Briggs 2004[47] Robinson 2011[56] Rocque 2017[59] Hickman 2016[62]
I26. Scripted Nurse pre-VAD Visits (USA) Guide included in article[63]	Face-to-face conversation in outpatient or inpatient setting	Patients at evaluation for VAD placement	Palliative Care nurse	Exact scripted conversation guide	Documentation in EHR Full palliative care consult if needed		O'Connor 2016[63]	
I27. Serious Illness Conversation Guide (USA) Guide available from: https://www.ariadnelabs.org/areas-of-work/serious-illness-care/	Single- or multiple-session face-to-face conversation at oncology care clinics	Seriously ill patients - patients with advanced incurable cancer and surrogates[91]	Clinicians (2.5-h training program)	Exact scripted conversation guide Patient pre-visit letter and guide Clinician reference guide	Structured documentation in EHR	Bernacki 2015[91,†]	Lakin 2017[64]	Lakin 2017[64]
I28. Sharing Patient's Illness Representations to Increase Trust (SPIRIT) (USA) Guide included in article[92]	Single- or double-session face-to-face conversation at outpatient clinic or home	Seriously ill patients Adapted for: ESRD[67,68] Heart failure with LVAD[65,66]	Trained nurse facilitator (3.5 d of training)	Exact scripted conversation guide Goals of Care document Information about AD	Placement of Goals of Care document in medical record	Song 2015[92] Song 2018[93,†]	Metzger 2016[65] Metzger 2016[66] Song 2009[67] Song 2015[68] Song 2016[76]	Metzger 2016[65] Metzger 2016[66] Song 2009[67] Song 2015[68] Song 2016[76] Song 2017[69]
I29. Structured intervention to facilitate EOL DM (Australia) Guide available from author[70]	Face-to-face conversation	Patients with metastatic cancer and their caregivers	Psychologist	Exact scripted conversation guide	DNR order as preferable documentation		Stein 2013[70]	Stein 2013[70]

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Table 2 (*continued*)

Intervention (Country) Accessibility	Characteristics Intervention					Included Publications		
	Mode, Schedule, and Setting	Target Population	Interventionist	Scripting and Materials	Treatment Implementation	Description Intervention	Feasibility Outcomes	Effect Outcomes
I30. The One Slide (South Africa) Guide included in article[71]	Face-to-face conversation	NS	Health care professionals, pastors, teachers	Exact scripted conversation guide	NS		Stanford 2013[71]	
I31. Thinking Ahead Project (TAP)* (USA) Copyrighted: guide based on I25, partially available from author[72]	Single-session face-to-face conversation combining MI with an adapted ACP interview at university medical center	Community-dwelling African Americans	A certified Respecting Choices Facilitator (additional 4-h MI-training)	Exact scripted conversation guide Package of ACP educational material with both the standard and health literacy adapted AD	Completion of AD		Huang 2016[72]	Huang 2016[72]
I32. Values-Based History (USA) Guide included in article[94]	Face-to-face conversation with follow-up sessions	Patients with serious illness	Health care providers	Conversation guide with question examples	Author states goal is to establish a concrete plan	Prommer 2010[94]		
I33. Value Discussion Guide (USA) Guide as appendix[73]	Facilitated face-to-face conversation after self-guided discussion at medical center or at home	Male veterans with AD and their surrogate	Psychologist	Exact scripted conversation guide	NS		Karel 2004[73]	Karel 2004[73]
I34. Voicing My Choices (USA) Guide included in article[95] https://fivewishes.org/docs/default-source/Samples/vmc-sample.pdf?sfvrsn=4	Face-to-face conversation	Adolescents and young adults with life-threatening conditions	Health care professionals	Conversation guide with question examples Guide functions as planning guide to document wishes	Guide can be used as a patient-held document to record the conversation	Zadeh 2015[95]	Smith 2017[74] Kazmerski 2016[75]	

AD, advance directive; CHF, congestive heart failure; COPD, chronic obstructive pulmonary disease; EHR, electronic health record; EOL, end of life; ESRD, end-stage renal disease; DM, decision making; DNR, do not resuscitate; GP, general practitioner; LVAD, left VAD; MI, motivational interviewing; NS, not specified; VAD, ventricular assist device.

*Conversation guide could not be fully analyzed because of loss of the complete guide (Intervention no.: 7) or copyright (Intervention no.: 13, 25, 31).

†Study protocol for randomized controlled trial.

‡Intervention developed in the USA, adapted for/implemented in Europe[51,87,88,90] and Singapore.[89]

Table 3
Synthesis of Framework for Structure and Content of Conversation Guides

General Structure of the Conversation Guides	
Preparation	Identification of eligible patients and creation of appropriate circumstances
Initiation	Setting up the conversation
Exploration	Eliciting patient's perspectives on relevant topics
Action	Translate content conversation into concrete steps

Content of Element	Themes in Conversation Guides	Covered in Guides, n (%)	Sample Statements (Intervention no.)
Initiation			
Readiness patient	Address current health state	4 (12%)	"A few months ago we spoke about what kind of care you would want if you were to become very ill. We're now facing that situation." (Intervention no.: 23) "I brought up these issues early so that you would have time to think about what's important to you. I'm not worried that anything will happen in the next weeks." (Intervention no.: 27)
	Attitudes to thinking about the future	11 (32%)	"Do you spend time thinking about your health and your future?" (Intervention no.: 6) "Do you think much about the future? What worries you when you think about the future? What are your hopes for the future?" (Intervention no.: 3)
	Ask permission for having the conversation	6 (18%)	"To adapt our therapy model to your personal needs, we need to know your preferences concerning some aspects that characterize our assistance. Do you wish to talk about them at this time?" (Intervention no.: 12) "Would you like to talk more about the kind of care you would want to have if you were no longer able to express your own wishes?" (Intervention no.: 22)
Rapport building	Establish relationship and trust	5 (15%)	"While I can't cure you, there are still many things I can do for you. I want you to be able to speak openly with me, so I can best help you. No matter what happens, I can be here for you—you are not alone." (Intervention no.: 23) "As your doctor, I want to make sure we are always doing the things that might help you, and that we never do anything that either can't help you, or you wouldn't want." (Intervention no.: 23)
Introduction	Concept of ACP and potential benefits	16 (47%)	"One thing I like to do with all my patients is to discuss advance care planning. Do you know what this means?" (Intervention no.: 10) "We want to help you stay in control of decisions about your care, and to ease things in case your family has to make difficult decisions on your behalf." (Intervention no.: 27)
	Framing future situation	5 (15%)	"These questions are pertaining to a situation in which you are either no longer able to express your wishes, or are in an unsound mental state for making rational decisions—that is, a situation when someone else will have to make medical decisions for you." (Intervention no.: 30)
	Clarifying conversation goals	11 (32%)	"I know this is hard to talk about, but I'd like to see if we can clarify a couple things about what your worries are about the future." (Intervention no.: 27) "We've talked about some of the key issues that are important as you get sicker, and I think it would be helpful to get a bit more specific about the types of treatments that do and don't make sense in your situation." (Intervention no.: 27)
	Consider invitation others	2 (6%)	"Is there someone you would like to be present with you for these conversations?" (Intervention no.: 11)
Exploration			
Illness views	Illness understanding	17 (50%)	"What do you understand about your illness or what's happening to you?" (Intervention no.: 11) "What is your understanding of your treatment options; your prognosis?" (Intervention no.: 16)
	Living with illness	13 (38%)	"How have you been feeling since you were given your diagnosis?" (Intervention no.: 4) "Tell me about living with COPD day-to-day?" (Intervention no.: 3)
Live views	Living well	19 (56%)	"What makes life worth living?" (Intervention no.: 3) "What activities or experiences are most important for you to live well?" (Intervention no.: 25)

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Table 3 (*continued*)

Content of Element	Themes in Conversation Guides	Covered in Guides, n (%)	Sample Statements (Intervention no.)
Views on death and dying	Prior experiences	7 (20%)	"How have you dealt with loss/death in the past? What do you wish had been different? What was OK for them, but would not be OK for you?" (Intervention no.: 6) "Have you or someone close to you had experiences with serious illness or death?" (Intervention no.: 8)
	Vision on end of life	13 (38%)	"We cannot predict exactly what medical treatment you might need at the end of your life. But it's important for me to know your thoughts about what type of medical care you would like to receive. How do you imagine spending your last days, weeks, and months?" (Intervention no.: 23) "Have you thought about dying (if they have not named this specifically)? Can you tell me more about these things?" (Intervention no.: 16)
Psychosocial well-being	Coping	8 (24%)	"When people get to this stage, some people feel like they want to keep fighting, and other people feel like they just want to be comfortable and let things happen as they may. How are you feeling now?" (Intervention no.: 23) "How are you coping with all of this?" (Intervention no.: 16)
	Fears and worries	19 (56%)	"What worries you most? What is your greatest fear? What helps with this worry and fear?" (Intervention no.: 3)
	Hope	7 (20%)	"As you think about how things are going with the illness, what are you hoping for?" (Intervention no.: 3)
	Religion and spirituality	10 (29%)	"Do you have any religious or spiritual beliefs that help you deal with difficult times? If so, tell about them." (Intervention no.: 24)
Planning and decision making	Prior experiences	12 (35%)	"Have you had any thoughts, discussions with your family or friends about what you would like to happen, if you become very ill and needed more support and care?" (Intervention no.: 4) "What experience do you have in making health-related choices (for self or others)?" (Intervention no.: 6)
	Locus of control	11 (32%)	"If there are any major decisions, do you prefer: for the doctors to make the decisions/for the doctors to give you all the information and help you make the decision/for you and your family to discuss and decide together/for you alone to make the decision/other?" (Intervention no.: 5) "What would you like to know about your care and treatment, how much information do you normally like to have? Are you the sort of person that likes to have all of the information, or would you prefer not to know too much?" (Intervention no.: 4)
	Goal setting	12 (35%)	"If your health situation worsens, what are your most important goals?" (Intervention no.: 27)
	Trade-offs	12 (35%)	"How much are you willing to go through for the possibility of gaining more time?" (Intervention no.: 27)
	Treatment preferences	32 (94%)	"The staff here will always try and advise what is in your best interests, and will discuss this with you whenever possible. It is helpful, however, to know if you have any particular preferences for or against specific treatments?" (Intervention no.: 6) "Are there certain treatments that you think you would never want? Why?" (Intervention no.: 5)
	Other preferences	11 (32%)	"If you could choose, would you prefer to die at home, in hospice, in residential care, or in hospital?" (Intervention no.: 11) "Do you have any specific religious or spiritual needs which you would like to be adhered to wherever you are cared for, such as attending a local church, or meeting place?" (Intervention no.: 12) "Do you have other preferences that we did not address?" (Intervention no.: 21)
	Documentation	7 (21%)	"Have you ever written down your wishes about future care or treatment?" (Intervention no.: 5)
Involvement of others	Family	21 (62%)	"Have you talked with your family about your health?" (Intervention no.: 16) "If they ask us, may we talk to your family about your illness? Is there anyone in your family whom you would prefer us not to give information to? Do you prefer anyone particular to be with you to hear results or to discuss and make important decisions about your care and treatments?" (Intervention no.: 5)

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Table 3 (*continued*)

Content of Element	Themes in Conversation Guides	Covered in Guides, n (%)	Sample Statements (Intervention no.)
	Professionals	8 (24%)	“How much does your primary care provider know about what’s important to you? What questions do you need to ask him or her?” (Intervention no.: 8) “What do you expect of your health care providers: availability? Information? Participation in decision making?” (Intervention no.: 6)
Action			
Summarize	Check understanding	8 (24%)	“You have previously said to me that when your time comes, we will let nature take its course. I will make sure that you are comfortable at all times, and that ultimately, you are able to die comfortably. We will not plan to use cardiopulmonary resuscitation or breathing machines or an intensive care unit. Am I correctly stating your preferences?” (Intervention no.: 23)
	Looking back on discussion	5 (15%)	“What was your goal regarding advance care planning or having a conversation, and how did it go?” (Intervention no.: 8)
	Recommendations	6 (18%)	“It sounds like … is very important to you. Given your goals and priorities and what we know about your illness at this stage, I recommend…” (Intervention no.: 27) “Based on the wide spread of your cancer, the fact that we have no more treatments to stop the growth of the cancer, and the fact that CPR doesn’t work for patients with metastatic cancer, I recommend that we focus intensively on your comfort, on helping you have as much time as possible with your family, and on getting you home.” (Intervention no.: 27)
Agreements	Surrogate decision maker	22 (65%)	“If you cannot, or choose not to participate in health care decisions, with whom should we speak?” (Intervention no.: 9) “Have you thought about who you might want to make decisions for you? If so, who?” (Intervention no.: 24)
	Documentation	17 (50%)	“Would you like any help with writing down your wishes and appointing the right person or people to act for you?” (Intervention no.: 30)
Follow-up	Next steps	12 (35%)	“What are your next steps regarding advance care planning?” (Intervention no.: 8)

trials ($n = 3$), the median total score of sufficiently met criteria was 3 (range 0–4). No trial met the criterion of blinding of participants. For observational studies ($n = 13$) and the quantitative part of mixed-method studies ($n = 11$), the median total score of sufficiently met criteria was 3 (range 1–5) and 1 (range 0–3), respectively. The assessment showed a low risk of bias regarding standardization of the ACP intervention[20,22,23,28,36,42,49,61–63,74] and standardization of outcome measurement in most studies.[16,23,28,36,42–44,48,59–62,74,75] For qualitative studies ($n = 13$), an assessment of the quality of reporting showed a median total score of sufficiently met criteria of 16.5 (range 12.5–29) (Appendix Table A7). For mixed-methods studies ($n = 11$), the median total score of sufficiently met criteria was 15 (range 3–18.5).

Intervention Characteristics

The 34 interventions were numbered and their characteristics summarized in Table 2. In general, 2 different designs of conversation guides were identified. About two-thirds of the interventions provided an exact scripted conversation guide (Intervention no.: 1, 2, 4, 5, 7, 9, 12–14, 17, 18, 21, 22, 24–31, 33). The other one-third provided guidance to the conversation by suggesting topics and prompts, but in a less structured format (Intervention no.: 3, 6, 8, 10, 11, 15, 16, 19, 20, 23, 32, 34).

Most identified interventions were developed for or tested in populations with serious illnesses (Intervention no.: 1–3, 6, 7, 11–16, 18, 20–23, 25–29, 32, 34). In some interventions, involvement of a surrogate decision maker was an essential part of the intervention (Intervention no.: 2, 4, 6, 13, 25, 27, 29, 33). Others left the decision to include a proxy to the patient. The interventionists had a broad range of professions, including physicians, nurses, social workers, patient navigators, and psychologists. Most interventions provided educational materials for the health care professional, the patient and family, or both. In about half of the interventions, some form of training of the interventionist was included, ranging from a couple of hours to multiple day courses.

Theoretical Background

Most articles reported on the development of the intervention which could involve a review of literature, expert panels with professionals and patients, and pilot testing.[7,19–22,26,29,38,39,41–47,63,71–73,79,80,84,91,92,94,95] A description of a theoretical background was often absent.[7,16,19–21,26,38,41,43–45,63,71,73,79,80,91,95,96]

Basic ethical principles were described by some authors as background for their intervention. Some stated that the ethical principle of patient autonomy played a central role in ACP originally, but that principles of communication and relational ethics had been introduced, focusing on a deeper conversation between the patient and health care professionals to identify and respect values of the patient and his psychosocial context.[17,18,39,78] Two authors used the concept of meaning-searching activities and legacy making in the intervention.[40,46] Others used the concept of motivational interviewing as a background for the design of the conversation guide.[42,72]

Table 4
Evidence From Trials

Author, Year, Country	Methods	Population n	Outcomes			Risk of Bias Total Score
			Decreased (Use of)	Increased (Use of)	No Difference (in Use of)	
I10. Communication about EOL Care Among patients with COPD						
Au 2012[24] USA	RCT Patient-specific feedback form vs standard form	Patients with COPD, N = 376 (I: 194 C: 182)		Quality of communication Discussions with surrogates Discussions with clinicians		2 of 6
Reinke 2017[25] USA	Subanalysis RCT Patient-specific feedback form vs standard form	Patients with COPD who died after study completion, N = 157			Documentation of EOL care discussions Completion of ADs Hospice referrals	2 of 6
I13. Family/Adolescents—Centered (FACE) ACP intervention						
Lyon 2009[29] USA	RCT FACE vs Adolescent Health Control Condition	Adolescents with HIV/AIDS, N = 38 dyads (I: 20, C:18)	Decisional conflict	Quality of communication Completion of AD	Dyad congruence	3 of 6
Lyon 2009[30] USA	”	”		Satisfaction with intervention		4 of 6
Lyon 2010[31] USA	”	”			Depression Anxiety Quality of life Likelihood to discontinue treatment	4 of 6
Lyon 2011[32] USA	”	”			Spirituality	3 of 6
Lyon 2013[33] USA	RCT FACE vs usual care	Adolescents with cancer, N = 30 dyads (I: 17, C: 13)	Decisional conflict	Dyad congruence Likelihood to discontinue treatment	Quality of communication	3 of 6
Lyon 2014[34] USA	”	”		Completion of AD	Anxiety Depression Quality of life Spiritual well-being	3 of 6
Dallas, 2016[37] USA	RCT FACE vs Adolescent Health Control Condition	Adolescents with HIV and surrogate, N = 97 dyads (I: 48, C: 49)		Self-report of both positive and negative emotions based on Satisfaction Questionnaire		4 of 6
Lyon 2017[35] USA	”	”		Dyad congruence Likelihood of treatment limitations	Leeway of surrogate regarding EOL decisions	4 of 6
I17. Let me Talk						
Chan 2010[40] China	Pre-post controlled trial Let me Talk vs usual care	Frail but competent nursing home residents, N = 121 (I: 59, C: 62)		Concordance on LST-preferences over time Quality of life Discussions with family or HCP		1 of 6
I22. Patient Navigator Intervention to improve palliative care						
Fischer, 2015[45] USA	RCT Patient navigator intervention vs information packet	Latino adults with life-limiting illness, n = 64 (I: 32, C: 32) Decedents after 12 mo, n = 18 (I: 10, C: 8)		Completion AD Documentation pain management	Outpatient pain medication order Hospice use	3 of 6
I24. Preserving Identity and Planning for Advance Care (PIPAC)						
Hilgeman 2014[46] USA	RCT PIPAC vs minimal support phone contact	Individuals with early dementia, N = 19 dyads (I: 11, C: 8)	Scale for Depression in Dementia Self-reported mobility dependence Decisional conflict	Subjective quality of life in dementia Coping strategies	Anxiety Quality of life in Alzheimer's disease Meaning in Life Scale Social engagement Emotional and Anticipated Support Scale	3 of 6
I25. Respecting Choices (RC)						
Schwartz 2002[54] USA	RCT RC vs local proxy form	Ambulatory geriatric patients, N = 61 (I: 31, C: 30)		ACP knowledge Dyad congruence Comfort proxy as decision maker	VAS pain, anxiety alertness	3 of 6
Briggs, 2004[47] USA	RCT RC vs usual care	Patients with ESRD, ESHF, HR-heart surgery, N = 27 dyads (I: 13, C: 14)	Decisional conflict	Quality of communication Dyad congruence	ACP knowledge	1 of 6

(*continued on next page*)

Table 4 (*continued*)

Author, Year, Country	Methods	Population n	Outcomes			Risk of Bias Total Score
			Decreased (Use of)	Increased (Use of)	No Difference (in Use of)	
Song 2005[55] USA	RCT RC vs usual care	Patients at cardiothoracic surgery clinic, N = 32 dyads (I: 16, C: 16)	Decisional conflict	Dyad congruence	Anxiety ACP knowledge	1 of 6
Song 2010[50] USA	RCT RC vs usual care	African Americans with stage 5 CKD, N = 17 dyads (I: 10, C: 7)		Quality of communication Dyad congruence Preference for LST	Decisional Conflict Self-perception and relationship Patient clinician interaction Cultural sensitivity clinician	4 of 6
Kirchhoff 2010[52] USA	RCT RC vs usual care	Patients with CHF or ESRD, N = 313 dyads (I: 160, C: 153)		ACP knowledge Dyad congruence		2 of 6
Kirchhoff 2012[53] USA	RCT RC vs usual care	Deceased patients with CHF or ESRD, N = 110 deaths (I: 62, C: 48)			Concordance preferences/EOL care	3 of 6
In der Schmitten 2014[51] Germany	Nonrandomized controlled trial Beizeiten Begleiten vs usual care	Nursing home patients, N = 575 (I: 136, C: 439)		Completion AD		0 of 6
I27. Serious Illness Conversation Guide (SICG)						
Lakin 2017[64] USA	Prospective implementation trial Clinics with SICG vs control clinics	Deceased patients in primary care clinic, N = 178 (I: 101, C: 77)		Documentation of conversations Comprehensiveness conversations	Discussion of prognosis, code status/LST or EOL planning Hospice use	2 of 6
I28. Sharing Patient's Illness Representations to Increase Trust (SPIRIT)						
Song 2015[68] USA	RCT, pre-posttest, SPIRIT vs usual care	Patients on dialysis therapy, n = 210 dyads (I: 109, C: 101), n = 45 bereaved surrogates (I: 28, C: 17)	Anxiety, depression and PTSS symptoms in surrogate after patient's death	Dyad congruence Decision-making confidence surrogate	Decisional conflict	4 of 6
Song, 2016[76] USA	RCT, pre-post test, SPIRIT vs usual care	Patients on dialysis therapy, n = 69 whites (I: 37, C: 32) n = 141 African Americans (I: 72, C: 69)	Decisional conflict Bereavement depressive symptoms surrogates	Dyad congruence Decision making confidence surrogates		4 of 6
I29. Structured intervention to facilitate end-of-life decision making						
Stein 2013[70] Australia	RCT, intervention vs usual care	Patients with metastatic cancer and carers, N = 120 patients (I: 55 [45 carers], C: 65 [52 carers])		Knowledge CPR	Anxiety Depression Caregivers reaction assessment DNR Hospital deaths	3 of 6

C, control; AD, advance directive; AIDS, acquired immune deficiency syndrome; CHF, congestive heart failure; CKD, chronic kidney disease; COPD, chronic obstructive pulmonary disease; dyads, patient and a proxy/surrogat decision maker/family member; EOL, end of life; ESHF, end-stage heart failure; ESRD, end-stage renal disease; HCP, health care practitioner; HIV, human immunodeficiency virus; HR, high risk; I, intervention; LST, life-sustaining treatment; PTSS, post-traumatic stress syndrome; RCT, randomized controlled trial; VAS, visual analog scale.

Six interventions (Intervention no.: 6, 13, 24, 25, 28, 31) were based on the representational approach of patient education. This theory is based on the Leventhal's description of illness along 5 identities (illness identity, cause, time line, consequences, and cure/control) and the conceptual change model.[97] Based on this theory, exploration of patient's perspectives on ACP themes and provision of patient-tailored information form the key steps in the conversation, resulting in highly individualized patient-specific processes.

Content of the Conversation Guides

We synthesized a summarizing framework of the structure and content of ACP conversation guides (Table 3). The main structural elements of the conversations guides consisted of 4 phases: preparation, initiation, exploration, and action. Sample statements, extracted from the conversation guides, are given in Table 3 to illustrate the content. The exploration phase contained the most elaborate statement samples.

Preparation and Initiation

The preparation phase consists of pre-conversational steps, including the identification of eligible patients and practical arrangements. The initiation phase is the start of the actual conversation in most interventions, containing different strategies to introduce ACP, to clarify the goal of the conversation and to establish a trustful relationship between patient and interventionist.

Exploration

In most conversation guides, the exploration of patient's views on multiple themes is the core part of the conversation. Illness understanding and views on living with illness are explored (Intervention no.: 2, 3, 6, 7, 11, 13–17, 20–29, 32) as well as views on living well (Intervention no.: 3, 4, 7, 11, 13, 16, 17, 21, 22, 24–26, 29, 32). Another key theme in the exploration phase is death and dying, covering both conceptual discussions about death and discussions about practical issues regarding the end of life (Intervention no.: 3, 6, 8, 12, 13, 16, 17, 19, 20, 22–25, 28, 29, 34). Themes related to the psychosocial well-being of the patient are addressed as well. Fears and worries are discussed (Intervention no.: 2, 3, 6–8, 11, 12, 14, 16–18, 20, 22, 24–28, 32) and hopes are explored (Intervention no.: 2, 3, 6, 17, 24, 25, 32) as well as sources of strength (Intervention no.: 12, 13, 17, 18, 24, 25, 29, 33, 34).

Planning and goal setting form a bridge between the exploration of personal values and the determination of preferences for future medical care. Personal views on planning and decision making are explored (Intervention no.: 2–4, 6, 8, 10, 11, 19, 22, 28, 33, 34). Patients' locus of control (Intervention no.: 1–6, 11, 12, 26, 27, 29, 34) and the desired involvement of family and professionals in care and decision making are discussed (Intervention no.: 1, 4–8, 11–13, 17, 19, 21, 22, 24–27, 29, 30, 32–34).

Goals of care (Intervention no.: 2, 6, 7, 11, 14, 16, 23, 25–28, 32) and trade-offs are defined to identify what the participant perceives as tolerable to achieve certain goals (Intervention no.: 3, 6, 8, 11, 12, 20, 23, 27, 28, 32, 33). Most interventions address treatment preferences (Intervention no.: 1, 2, 5, 6, 8–17, 19–21, 23–26, 29, 30, 32, 34). Some interventions use scenarios or mentioned specific therapies; others evaluate treatment preferences more in general. Some interventions evaluate whether the patient has or would like to have preferences documented in a (legal) document (Intervention no.: 3, 5, 11, 19, 20, 25, 29, 30).

Action

The last phase of the conversation guide could include a summary (Intervention no.: 2–4, 10, 11, 14, 19, 22, 23, 25, 27, 28, 32). Only few interventions make patient-specific recommendations based on the prior explorative phase (Intervention no.: 10, 11, 23, 25, 27, 32). Most interventions propose designation of a surrogate decision maker as a concrete action at the end of the conversation (Intervention no.: 1–4, 6, 8, 9, 11, 13, 17, 20, 22–26, 28–30, 32–34). Documentation forms range from notes in the patients' medical record to written documents like advance directives, do-not-resuscitate orders, or living wills (Intervention no.: 1, 2, 8, 14–16, 19, 20, 22–25, 32). One intervention is based on a patient-held document and left the dissemination to the patient (Intervention no.: 34). Additional steps could consist of planning follow-up conversations to discuss strategies to share the content of the conversation with family and other health care providers.

Other Content of the Conversation Guide

Some guides provide examples of "guidance-on-the-job" by the professional as a longitudinal element throughout the conversations (Intervention no.: 2, 10, 16, 19, 22–25, 27, 28, 34). These are parts of the conversation in which the professional gives information to clarify certain topics or procedures. This includes information about the illness (current state and prognosis), the concept of ACP and surrogate decision makers, specific treatment options, expected patient-specific outcomes, options for documentation, and legal issues.

Feasibility and Effectiveness

Empirical data on the interventions were very heterogeneous because of varying study designs and outcome measures. Inclusion of patients in the studies seemed to be challenging, as reflected by a wide range of eligibility rates and a participant refusal rate of more than 50% in multiple studies.[22–24,45,48,51,54,55,73] Reported reasons for refusal were as follows: already having an advance directive or being engaged in an ACP discussion, lack of interest, and logistic problems (too busy and traveling issues).[22,23,45,55] After inclusion, the completion rate of the interventions was >75% in most studies.[22–24,29,30,35–37,40,42,43,46,47,49,51,63] Two studies reported much lower completion rates. In one study, evaluating a 2-step interview, only 33% of the participants completed the full interview, including the second part concerning death and dying.[26] Another study evaluated a program with 5 visits from a patient navigator.[45] Only 31% of the participants received all visits.

Eleven interventions were evaluated in a randomized[24,25,29–35,37,40,45–47,50–55,64,68,70,76] or nonrandomized controlled trial.[40,51,64] The main body of evidence concerns 3 interventions: Respecting Choices (n = 6 trials described in 7 articles),[47,50–55] SPIRIT (n = 4 trials, described in 6 articles),[65–69,76] and FACE (n = 3 trials, described in 10 articles).[28–37]

Measurements in randomized controlled trials focused on process measures such as knowledge about ACP, documentation rates, discussion rates, quality of communication, decisional conflict, and dyad congruence on treatment preferences (Table 4). Dyad congruence and documentation rates improved because of the interventions.[29,33–35,45,47,51,52,54,55,64,68,76] For the remaining process measures results were mixed. Measurements of quality of life, psychosocial well-being, hospice use, and concordance of preferences and received care were used less often and the results were mixed as well.

Twelve observational studies and 9 mixed-methods studies showed similar results, reporting a positive trend toward sharing of information with surrogates[22,23,35,42,65,67] and improved documentation rates (Tables 5 and 6).[16,23,42,43,48,49,60,61] Studies evaluating patient's perspectives on ACP conversations reported a perceived positive experience.[20,22,28,42,67,72,75]

Qualitative data showed that participation in ACP conversations was experienced as positive and beneficial by participants on the one hand (Appendix Table A7).[17–19,21,22,43,56,65–67,69,72] On the other hand, the conversations were also described as difficult and emotional.[17,56,57,66,67,73] ACP conversations had a positive influence on relationships with relatives and surrogate decision makers.[18,19,56,66,67,69,73]

Discussion

Findings

To our knowledge, this is the first systematic review evaluating the content, feasibility, and effectiveness of interventions based on a conversation guide to support health care professionals in ACP conversations. Thirty-four unique interventions were identified. Most interventions lacked a comprehensive theoretical underpinning. A thematic analysis of identified conversation guides revealed 4 subsequent phases of ACP conversations: preparation, initiation, exploration, and action. The explorative phase formed the core part of the conversation guides discussing illness views, views on living well, views on death and dying, psychosocial well-being, treatment preferences, and views on involvement of others in care and decision making. The connection between the distinct phases of the conversation was less well described in most interventions. How prior phases inform the action phase and subsequent steps in the ACP process remains unclear. Although guided ACP conversations seem to increase dyad congruence and ACP documentation rates, the evidence for effects on future medical care and preferences-concordant care is limited.

High-quality research answering underlying key questions about the process and effectiveness of ACP is still in its infancy. The evidence identified in this review is concentrated around a few interventions and does not enable comparison between individual interventions or conversation guides. It remains unclear which conversation themes are most helpful in ACP.

Several factors complicate research about ACP interventions. First, these interventions are often complex interventions, consisting of multiple interacting components, which makes their evaluation more challenging.[98] In our review, this was reflected by the heterogeneity of intervention descriptions, study designs, outcome measures, and study quality. Besides that, the absence of details about the intervention in manuscripts is a generally acknowledged phenomenon.[99]

Table 5
Evidence From Observational Studies

Author, year, Country	Aim and Methods	Population n	Outcomes	Risk of Bias Total Score
I1. ACP for adults with congenital/pediatric heart disease				
Edwards 2017[16] USA	To report results of quality improvement project for ACP Chart review	Patients aged $\geq$18 y at Heart Failure and Transplant Clinic, N = 58	At baseline, no documented ACP discussions or AD, after 1 y 75% of adult encounters had a documented ACP discussion and 42% had a documented AD	2 of 7
I5. ACP in geriatric patients				
Friis 2015[20] USA	To test the feasibility of systematic ACP discussions Categorized patient reports	Patients admitted to geriatric ward of hospital, N = 58	Discussions were rated as: a positive experience in 72%, a reasonable experience in 26% and a stressful experience in 2% “One half” formulated wishes for future treatment during the discussion	1 of 7
I13. Family/Adolescents−Centered (FACE) ACP intervention				
Jacobs 2016[28] USA	To report perspectives regarding EOL care Survey study from intervention arm RCT	Adolescents with cancer, n = 17 dyads, n = 30 clinicians	Adolescent preferred EOL discussions in 75%, not only “if dying” and felt comfortable about talking about death in 54%. 12% felt not at all comfortable Providers felt in 83% their patients’ participation in the study was helpful to the patients, and 78% felt it was helpful to them as providers. No one thought it was harmful for patients. In addition, 77% would refer patients to an ACP team	5 of 7
Lyon 2017[35] USA	To identify ACP needs and related dyad congruence Survey study from intervention arm RCT	Adolescents with HIV and surrogates, N = 48 dyads	Adolescent and family concordance: substantial congruence in that being free from pain and understanding your treatment choices were very important or important. There was discordance about being off machines that extend life and when is the best time to bring up EOL decisions	5 of 7
I16. Kitchen Table Discussion				
Ratner 2001[39] USA	To determine effect of ACP intervention on home death Case series	Patients receiving home care services, N = 84	99% agreed to discuss EOL-issues with social worker 64% expressed location for EOL care, which was home in 85% 70% of the deceased patients died at home	2 of 7
I19. Motivational Stage-Tailored Intervention to ACP				
Ko 2016[42] USA	To test feasibility of the intervention Pre-posttest structured questionnaire study	Low income adults aged >60 y from a supportive housing facility, N = 30	Engagement in EOL discussions: 33% preintervention vs 47% postintervention Change in behavioral change stages: preintervention: 10% planning stage, 0% active stage. Postintervention: 47% planning stage, 23% active stage Increase of ACP knowledge and positive attitudes toward ACP (perceived importance and self-efficacy). No differences in negative attitudes toward ACP 20% appointed a DPA and 83% of them had an EOL discussion with that DPA 23% completed an AD postintervention, of which 86% were unsigned Most participants were receptive towards the intervention and considered it beneficial	3 of 7

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Table 5 (*continued*)

Author, year, Country	Aim and Methods	Population n	Outcomes	Risk of Bias Total Score
I25. Respecting Choices (RC)				
Hammes 2010[60] USA	To determine outcome change over time for RC Retrospective review EHR and death certificate data pre/post implementation	All adult deaths in specific region in 2 time periods, N = 940 (T1 n = 540, T2 n = 400)	Increased prevalence, availability and specificity of advance care plans after implementation of RC After implementation of RC increase of time period between completion of AD and death Increased consistency between patient preferences and treatment provided after implementation of RC	3 of 7
Boettcher 2014[48] USA	To test feasibility of telephonic ACP Prospective descriptive study data	Frail elderly patients with multiple comorbidities/advanced disease, n = 576 Facilitators, n = 16	Telephonic ACP resulted in advance directive: in 55 of 56 discussions Increased motivation, confidence, and feeling prepared and skilled among facilitators 3 mo postintervention. This decreased after 6 mo	1 of 7
Hall 2014[49] USA	To evaluate implementation of RC Review EHR and questionnaire study	Residents of assisted living facilities with limited life expectancy and their health care agents N = 10 dyads	Overall quality of patient-clinician interaction rated as excellent in 90%. All residents and 88% of surrogates were sure the clinician knew their treatment preferences, cared about them as a person, listened to what they said and gave enough attention Number and type of orders in POLST documents: all residents had a CPR order and orders on specific medical treatments (intubation, artificially administered nutrition and hydration, antibiotic use)	3 of 7
Pecanac 2016[61] USA	To determine effect RC on AD prevalence and utilization Retrospective review EHR pre/post implementation	Medical records of all decedents from 2005 to 2010 in a 300-bed Midwestern metropolitan hospital N = 732	Increased prevalence of AD's in racial or ethnic minorities after implementation of RC. In whites no difference. Consistency of wishes with treatment received was high for all orders; no difference after implementation of RC, no racial/ethnic differences.	5 of 7
Hickman 2016[92] USA	To describe processes and preliminary outcomes from implementation RC-based ACP intervention Descriptive study data and review EHR	Long-stay nursing home residents, N = 2709	Engagement in ACP discussion: 27% Change in documented preferences in 69% after ACP discussion(s) Review EHR: documentation about ACP conversation present in 42%. Key reasons for absence of ACP conversations: "not gotten to the resident yet" (57.6%), resident qualified as ineligible (20.9%), difficulty scheduling (9.8%)	3 of 7
I34. Voicing My Choices (VMC)				
Smith 2017[74] USA	To evaluate the use of VMC in a simulated setting Pre-posttest questionnaire study	Nurse providers, N = 18	Simulation exercise with VMC guide increased self-confidence regarding initiation of ACP and ability/skills to discuss ACP	3 of 7
Kazmerski 2016[75] USA	To assess patient and provider attitudes and preferences regarding VCM	Patients aged $\leq$22 y with advanced CF, n = 12 Providers, n = 7	Patients felt sessions helpful in 83% and 58% were satisfied with the session One patient felt angry, afraid, or overwhelmed during the session, no one felt ACP was harmful Patients felt the VCM guide easy to understand and appropriate for CF in 90% Providers felt the guide helpful and easy to understand, and easy to use in leading an ACP discussion, and all providers felt it appropriate for someone with CF	2 of 7

AD, advance directive; CF, cystic fibrosis; DPA, durable power of attorney; EHR, electronic health record; EOL, end of life; HIV, human immunodeficiency virus; POLST, physician orders for life sustaining treatment; RCT, randomized controlled trial.

Table 6
Evidence From Mixed-Method Studies

Author, Year, Country	Aim and Methods	Population no.	Outcomes		Risk of Bias Total Score	Quality of Reporting Total Score
			Quantitative Data	Qualitative Data		
I8. ACP Group Medical Visit						
Lum 2016[22] USA	To report feasibility of Group Medical Visits Electronic patients reports and content analysis group visits	Geriatric patients receiving primary care, N = 32	Post-intervention 75% had an ACP conversation with surrogate and 41% felt confident loved ones know their wishes Group Visits were rated better for ACP talk than usual visits and gave useful information 80% felt comfortable about ACP talk in groups and 70% stated talking with others about ACP was helpful	Patients shared personal values and challenges related to ACP Patients initiated group discussions of a broad range of ACP topics beyond topics raised by facilitators	1 of 7	18.5 of 32
Lum 2017[23] USA	To report feasibility of Group Medical Visits Chart review and content analysis group visits	Patients aged ≥65 y in primary care, N = 118	82% completed both intervention sessions Increased documentation of surrogate decision maker in EHR over study period Increased amount of ACP documents in EHR over the study period	Key reasons for participating: recognition need for ACP, recommendation by primary care providers, curiosity about the topic	3 of 7	14.5 of 32
I12. End of Life Preferences Interview (ELPI)						
Borreani 2008[26] Italy	To pretest feasibility of ELPI Descriptive study data and semi-structured interviews of physicians	Palliative care patients, n = 12 Physicians, n = 3	Physicians proposed ACP in 27% of eligible patients. Reasons behind refusal to propose: finding the right time and moment Completion of first part intervention: 67%, completion of full intervention: 33%	Physicians pointed out that the condition necessary to propose the interview to the patient is his or her awareness about the prognosis. Physicians were comfortable about confronting proposed themes, but fear of triggering intense emotions exists. ELPI is stimulus for conversation but somewhat direct, with limited possibilities for adaptation	0 of 7	8.5 of 32
Borreani 2012[27] Italy	To test feasibility of ELPI Descriptive study data and open-response questionnaire	Advanced cancer patients in palliative care setting, n = 91 Physicians, n = 23	Physicians proposed ACP in 58% of eligible patients. Reasons refusal to propose: logistic-organizational reasons, poor physical condition of patient, other reasons Completion of full intervention: 42%	Factors influencing communication: patient and family readiness, physician willingness, skills and team support, sufficient time and adequate timing	0 of 7	12 of 32

(*continued on next page*)

Table 6 (*continued*)

Author, Year, Country	Aim and Methods	Population no.	Outcomes		Risk of Bias Total Score	Quality of Reporting Total Score
			Quantitative Data	Qualitative Data		
I20. Palliative Care Program (PCP)						
Chan 2014[43] China	To report effectiveness of PCP Pre-posttest questionnaire study and semistructured interview study	Home care patients with life-limiting disease, n = 108 (quantitative outcomes) n = 14 (qualitative outcomes)	Improved physical quality of life and decreased need for social support Improved understanding treatment and goals Family satisfaction tended to improve Initial decrease in hospital use, reduced effect after 3 mo Initial increase in completion AD/living will/DNR order, reduced effect after 3 mo	Improved communication of treatment plans and after-death arrangement Relief of fear Improvement of emotional support Improvement of symptom management by home care nurses	1 of 7	15 of 32
I21. Patient Preferences About Serious Illness Instrument (PASI)						
Whitehead 2016[44] USA	To understand effectiveness of PASI and report on experiences in EOL conversations Survey study and focus group	Nurse practitioners, n = 47 (quantitative outcomes), n = 13 (qualitative outcomes)	68% were currently having conversations about EOL preferences with patients. 32% did not, but were interested in having them 89% agreed to be comfortable having EOL conversations with patients	Formal training to conduct EOL conversations is needed PASI could improve care, is useful and can identify a patient's primary concern	1 of 7	17 of 32
I25. Respecting Choices (RC)						
Rocque 2017[59] USA	To evaluate implementation of lay navigator-led RC-based ACP Review EHR, claims data, questionnaire and semistructured interviews	Lay patient navigators, n = 26 Patients from 12 cancer centers, n = 8704	ACP conversations were initiated in 15% of patients and 36% completed the conversation Navigators' self-efficacy increased during the study Lower hospitalization rates in patient engaged in ACP discussions	Navigator-reported facilitators for implantation included physician buy-in, patient readiness, and prior ACP experience; barriers included space limitations, identifying the "right" time to start conversations, and personal discomfort discussing EOL	1 of 7	15 of 32
I26. Scripted Nurse pre-Ventricular Assisted Device Visits						
O'Connor 2016[63] USA	To evaluate ACP program Prospective descriptive study data and interviews	Patients for VAD evaluation, n = 37 VAD team members, n = 4	All eligible patients agreed to the visit and completed the entire scripted visit	VAD team uniformly positive, declared visits as "valuable"	2 of 7	3 of 32
I28. Sharing Patient's Illness Representations to Increase Trust (SPIRIT)						
Song 2009[67] USA	To determine feasibility, acceptability, and effects of SPIRIT vs usual care RCT, pre-posttest, questionnaires and semistructured interviews	African Americans with ESRD, n = 58 dyads (I: 29, C: 29) Bereaved surrogates, n = 4 (I: 4, C: 0)	Increase in quality of communication and dyad congruence No difference in decisional conflict, psychosocial and spiritual well-being and surrogate's decision-making confidence	ACP made it easy to open up and share feelings. ACP was emotional but profitable SPIRIT increased knowledge and insight in values, LST, and family dynamics. Patient-family relation was strengthened Three bereaved surrogates made EOL decisions for a patient, they were well prepared, and SPIRIT helped in decision making.	3 of 7	17 of 32

(*continued on next page*)

Table 6 (*continued*)

Author, Year, Country	Aim and Methods	Population no.	Outcomes		Risk of Bias Total Score	Quality of Reporting Total Score
			Quantitative Data	Qualitative Data		
Metzger 2016[65] USA	To examine feasibility, acceptability, and preliminary effects of SPIRIT-HF vs usual care RCT, descriptive study data, questionnaires, and semistructured interviews	Heart failure patients with LVAD, N = 29 dyads (I: 14, C: 15)	21% of eligible patients declined Increase in dyad congruence No difference in decisional conflict and surrogate DM confidence	Twenty-five participants had a positive experience, 3 mixed All participants declared conversations like SPIRIT-HF very important Nearly all declared these conversations should be part of patient care Benefits: being able to express preferences for EOL care; learning about EOL scenarios and DM; being prepared for "what-ifs" Most common barriers: timing and scheduling	3 of 7	14.5 of 32
I31. Thinking Ahead Project (TAP)						
Huang 2016[72] USA	To examine the feasibility of TAP vs provision of education materials RCT, descriptive study data, questionnaires, and semistructured interviews	Community-dwelling African Americans, n = 30 (I: 15, C: 15) Waitlist controls received intervention after waiting time, n = 12	Increased knowledge of ADs in intervention group No difference in satisfaction with intervention or intention to complete AD	Participants noted that the TAP intervention was "very well covered" and "helped to make ACP simpler to understand." Low engagement in ACP among African Americans due to lack of information and patient education resources Participants expressed a strong desire to learn more about ACP and have education or information delivered to the local community to meet their health literacy needs	1 of 7	15 of 32

AD, advance directive; C, control; EHR, electronic health record; EOL, end of life; ESRD, end-stage renal disease; DM, decision making; DNR, do-not-resuscitate; I, intervention; LST, life-sustaining treatment; RCT, randomized controlled trial; LVAD, left VAD; VAD, ventricular assist device.

More transparency about the content of interventions is a first step toward more insight in ACP interventions.

Second, the evaluation of ACP interventions is mainly based on process measures like knowledge about ACP, documentation rates, discussion rates, quality of communication, and dyad congruence. Although these parameters might influence the effectiveness of ACP interventions, improvement of process factors does not ensure achievement of the final goal of ACP, which is "to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness."[100]

Third, an underlying rationale for the characteristics of the interventions and content of the guides was often lacking. The practice-based design of ACP conversation guides complicates the understanding of the communicative process and illustrates the need for research to reveal underlying communicative, relational, and behavioral principles.[101,102]

Our review shows there is a large body of existing interventions. The growing interest in ACP should therefore not result in the development of more new interventions, but in deeper evaluation of current strategies to understand which (components of) ACP interventions are effective and why.

The key question remains as to how exploration of patient's perspectives can be used to inform future medical decision making and care. The translation of preferences and values into goals of care and treatment decisions requires further identification of essential content of the conversation and the role, attitude, and position of the conversation partners. The professional might have a predominantly initiating, facilitating, and explorative role, but providing guidance to the patient based on the patient's values and preferences on the one hand and medical expertise on the other might be another task of the health care professional.[6,80,94] This "skilled companionship" might be essential to strengthen the translation of values, life goals, and preferences into corresponding medical care in different stages of life and illness. Content analysis of ACP conversations and thorough, longitudinal evaluation of patient's perspectives on the value of ACP might help in understanding this complex, individualized process.

Strengths and Limitations

This systematic review provides a thorough overview of the body of knowledge regarding multiple dimensions of ACP interventions based on conversation guides. Instead of a focus on outcome data, it evaluates the characteristics of the interventions and the content of the conversation guides as well.

Our review has some limitations. First, although 34 interventions were retrieved, the identification of articles describing scripted conversation guides might not be complete. Although corresponding authors were contacted to obtain more details on the intervention characteristics, studies might have been excluded inaccurately because of lack of insight into the conversation guide. Second, nonprofit organizations, patient organizations, and governmental initiatives respond to the growing attention for ACP with the development of ACP tools. These tools are often only described in gray literature and were not covered by our search, but might play a role in daily medical care.

Third, our review did not include interventions based on websites, patient-held workbooks, patient question-prompt lists, and games.[103–105] These interventions may result in similar ACP conversations compared to interventions based on a scripted conversation guide. The choice not to evaluate other approaches limits the evaluation of the added value of a scripted conversation guide.

Conclusions

Scripted ACP conversation guides structure ACP discussions in 4 phases: preparation, initiation, exploration, and action. Exploration of patient's views on illness, living well, EOL issues, and decision making form the core part of ACP conversation guides. This exploration might support the professional to align medical care with patients' preferences. Research evaluating the relation between guided ACP conversations and preferences-concordant care is limited. Further research needs to reveal underlying theoretical and communicative principles to determine which elements are essential to connect exploration of values and preferences with future medical care.

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Supplementary data

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References

1. Institute of Medicine. Committee on approaching death: Addressing key end-of-life issues, Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. Washington, DC: National Academies Press; 2015.
2. Rietjens JAC, Sudore PRL, Connolly M, et al. Review definition and recommendations for advance care planning: An international consensus supported by the European Association for Palliative Care. Lancet Oncol 2017;18: e543–e551.
3. Brinkman-Stoppelenburg A, Rietjens JAC, van der Heide A. The effects of advance care planning on end-of-life care: A systematic review. Palliat Med 2014;28:1000–1025.
4. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: Randomised controlled trial. BMJ 2010;340:c1345.
5. Houben CHM, Spruit MA, Groenen MTJ, et al. Efficacy of advance care planning: A systematic review and meta-analysis. J Am Med Dir Assoc 2014;15: 477–489.
6. Bernacki RE, Block SD. Communication about serious illness care goals: A review and synthesis of best practices. JAMA Intern Med 2014;174:1994–2003.
7. De Vleminck A, Houttekier D, Deliens L, et al. Development of a complex intervention to support the initiation of advance care planning by general practitioners in patients at risk of deteriorating or dying: A phase 0-1 study. BMC Palliat Care 2016;15:17.
8. Gilissen J, Pivodic L, Smets T, et al. Preconditions for successful advance care planning in nursing homes: A systematic review. Int J Nurs Stud 2017;66: 47–59.
9. Moher D, Liberati A, Tetzlaff J, Altman DG. Prisma Group. Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. Ann Intern Med 2009;6:e1000097.
10. Schulz R, Czaja SJ, McKay JR, et al. Intervention Taxonomy (ITAX): Describing essential features of interventions. Am J Health Behav 2010;34:811–821.
11. Higgins J, Green S, editors. Cochrane Handbook for Systematic Reviews of Interventions. Version 5. London, United Kingdom: The Cochrane Collaboration. Available at: http://handbook.cochrane.org; 2011. Accessed May 1, 2017.
12. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): A 32-item checklist for interviews and focus groups. Int J Qual Health Care 2007;19:349–357.
13. Dixon-Woods M, Shaw RL, Agarwal S, Smith JA. The problem of appraising qualitative research. Qual Saf Health Care 2004;13:223–225.
14. Popay J, Roberts H, Sowden A, et al. Guidance on the Conduct of Narrative Synthesis in Systematic Reviews: A Product from the ESRC Methods Programme. London, United Kingdom: Institute for Health Research; 2006.
15. Thomas J, Harden A. Methods for the thematic synthesis of qualitative research in systematic reviews. BMC Med Res Methodol 2008; 10:1–10.
16. Edwards LA, Jarrell JA, Bui C, Cabrera AG. Improving outpatient advance care planning for adults with congenital or pediatric heart disease followed in a pediatric heart failure and transplant clinic. Congenit Heart Dis 2018;13: 362–368.
17. Simpson AC. An opportunity to care? Preliminary insights from a qualitative study on advance care planning in advanced COPD. Prog Palliat Care 2011;19: 243–253.
18. Simpson C. Advance care planning in COPD: Care versus "code status." Chron Respir Dis 2012;9:193–204.
19. Poppe M, Burleigh S, Banerjee S. Qualitative evaluation of advanced care planning in Early dementia (ACP-ED). PLoS One 2013;8.
20. Friis P, Forde R. Advance care planning discussions with geriatric patients. Tidsskr Nor Laegeforening 2015;135:233–235.
21. Horne G, Seymour J, Shepherd K. Advance care planning for patients with inoperable lung cancer. Int J Palliat Nurs 2006;12:172–178.
22. Lum HD, Jones J, Matlock DD, et al. Advance care planning meets group medical visits: The feasibility of promoting conversations. Ann Fam Med 2016;14:125–132.
23. Lum HD, Sudore RL, Matlock DD, et al. A group visit initiative improves advance care planning documentation among older adults in primary care. J Am Board Fam Med 2017;30:480–490.
24. Au DH, Udris EM, Engelberg RA, et al. A randomized trial to improve communication about end-of-life care among patients with COPD. Chest 2012;141:726–735.
25. Reinke LF, Feemster LC, McDowell J, et al. The long term impact of an end-of-life communication intervention among veterans with COPD. Heart Lung J Acute Crit Care 2017;46:30–34.
26. Borreani C, Brunelli C, Miccinesi G, et al. Eliciting individual preferences about death: Development of the end-of-life preferences interview. J Pain Symptom Manage 2008;36:335–350.
27. Borreani C, Brunelli C, Bianchi E, et al. Talking about end-of-life preferences with advanced cancer patients: Factors influencing feasibility. J Pain Symptom Manage 2012;43:739–746.
28. Jacobs S, Perez J, Cheng YI, et al. Adolescent end of life preferences and congruence with their parents' preferences: Results of a survey of adolescents with cancer. Pediatr Blood Cancer 2015;62:710–714.
29. Lyon ME, Garvie PA, Briggs L, et al. Development, feasibility, and acceptability of the family/Adolescent-centered (FACE) advance care planning intervention for adolescents with HIV. J Palliat Med 2009;12:363–372.
30. Lyon ME, Garvie PA, McCarter R, et al. Who will speak for me? Improving end-of-life decision-making for adolescents with HIV and their families. Pediatrics 2009;123:e199–e206.
31. Lyon ME, Garvie PA, Briggs L, et al. Is it safe? Talking to teens with HIV/AIDS about death and dying: A 3-month evaluation of family centered advance care (FACE) planning—Anxiety, depression, quality of life. HIV/AIDS Res Palliat Care 2010;2:27–37.
32. Lyon ME, Garvie PA, Kao E, et al. Spirituality in HIV-infected adolescents and their families: FAmily CEntered (FACE) advance care planning and medication adherence. J Adolesc Health 2011;48:633–636.
33. Lyon ME, Jacobs S, Briggs L, et al. Family-centered advance care planning for teens with cancer. JAMA Pediatr 2013;167:460–467.
34. Lyon ME, Jacobs S, Briggs L, et al. A longitudinal, randomized, controlled trial of advance care planning for teens with cancer: Anxiety, depression, quality of life, advance directives, spirituality. J Adolesc Health 2014;54: 710–717.
35. Lyon ME, D'Angelo LJ, Dallas RH, et al. A randomized clinical trial of adolescents with HIV/AIDS: Pediatric advance care planning. AIDS Care 2017;29: 1287–1296.
36. Lyon ME, Dallas RH, Garvie PA, et al. Paediatric advance care planning survey: A cross-sectional examination of congruence and discordance between

adolescents with HIV/AIDS and their families. BMJ Support Palliat Care 2017;0:1–9.
37. Dallas RH, Kimmel A, Wilkins ML, et al. Acceptability of family-centered advanced care planning for adolescents with HIV. Pediatrics 2016;138: e20161854.
38. Bekelman DB, Johnson-Koenke R, Ahluwalia SC, et al. Development and feasibility of a structured goals of care communication guide. J Palliat Med 2017;20. jpm.2016.0383.
39. Ratner E, Norlander L, McSteen K. Death at home following a targeted advance-care planning process at home: The kitchen table discussion. J Am Geriatr Soc 2001;49:778–781.
40. Chan HYL, Pang SMC. Let Me Talk—an advance care planning programme for frail nursing home residents. J Clin Nurs 2010;19:3073–3084.
41. Schwartz C, Lennes I, Hammes B, et al. Honing an advance care planning intervention using qualitative analysis: The Living Well interview. J Palliat Med 2003;6:593–603.
42. Ko E, Hohman M, Lee J, et al. Feasibility and acceptability of a brief motivational stage-tailored intervention to advance care planning. Am J Hosp Palliat Med 2016;33:834–842.
43. Chan CWH, Chui YY, Chair SY, et al. The evaluation of a palliative care programme for people suffering from life-limiting diseases. J Clin Nurs 2014;23: 113–123.
44. Whitehead PB, Ramalingam N, Carter KF, et al. Nurse practitioners' perspectives on the patient preferences about serious illness instrument. J Hosp Palliat Nurs 2016;18:332–341.
45. Fischer SM, Cervantes L, Fink RM, Kutner JS. Apoyo con Carino: A pilot randomized controlled trial of a patient navigator intervention to improve palliative care outcomes for Latinos with serious illness. J Pain Symptom Manage 2015;49:657–665.
46. Hilgeman MM, Allen RS, Snow AL, et al. Preserving Identity and Planning for Advance Care (PIPAC): Preliminary outcomes from a patient-centered intervention for individuals with mild dementia. Aging Ment Health 2014;18: 411–424.
47. Briggs LA, Kirchhoff KT, Hammes BJ, et al. Patient-centered advance care planning in special patient populations: A pilot study. J Prof Nurs 2004;20: 47–58.
48. Boettcher I, Turner R, Briggs L. Telephonic advance care planning facilitated by health plan case managers. Palliat Support Care 2015;13:795–800.
49. Hall NA, Jenson CE. Implementation of a facilitated advance care planning process in an assisted living facility. J Hosp Palliat Nurs 2014;16:113–119.
50. Song MK, Donovan HS, Piraino BM, et al. Effects of an intervention to improve communication about end-of-life care among African Americans with chronic kidney disease. Appl Nurs Res 2010;23:65–72.
51. Der Schmitten JI, Lex K, Mellert C, et al. Implementing an advance care planning program in German nursing homes. Dtsch Arztebl Int 2014;111: 50–57.
52. Kirchhoff KT, Hammes BJ, Kehl KA, et al. Effect of a disease-specific planning intervention on surrogate understanding of patient goals for future medical treatment. J Am Geriatr Soc 2010;58:1233–1240.
53. Kirchhoff KT, Hammes BJ, Kehl KA, et al. Effect of a disease-specific advance care planning intervention on end-of-life care. J Am Geriatr Soc 2012;60: 946–950.
54. Schwartz CE, Wheeler HB, Hammes B, et al. Early intervention in planning end-of-life care with ambulatory geriatric patients: Results of a pilot trial. Arch Intern Med 2002;162:1611–1618.
55. Song MK, Kirchhoff KT, Douglas J, et al. A randomized, controlled trial to improve advance care planning among patients undergoing cardiac surgery. Med Care 2005;43:1049–1053.
56. Robinson CA. Advance care planning: Re-visioning our ethical approach. Can J Nurs Res 2011;43:18–37.
57. Robinson CA. "Our best hope is a cure." Hope in the context of advance care planning. Palliat Support Care 2012;10:75–82.
58. Niranjan SJ, Huang CHS, Dionne-Odom JN, et al. Lay patient navigators' perspectives of barriers, facilitators and training needs in initiating advance care planning conversations with older patients with cancer. J Palliat Care 2018; 33:70–78.
59. Rocque GB, Dionne-Odom JN, Sylvia Huang CH, et al. Implementation and impact of patient lay navigator-led advance care planning conversations. J Pain Symptom Manage 2017;53:682–692.
60. Hammes BJ, Rooney BL, Gundrum JD. A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. J Am Geriatr Soc 2010;58:1249–1255.
61. Pecanac KE, Repenshek MF, Tennenbaum D, Hammes BJ. Respecting choices and advance directives in a diverse community. J Palliat Med 2014;17: 282–287.
62. Hickman SE, Unroe KT, Ersek MT, et al. An interim analysis of an advance care planning intervention in the nursing home setting. J Am Geriatr Soc 2016;64: 2385–2392.
63. O'Connor NR, Moyer ME, Kirkpatrick JN. Scripted nurse visits: A resource-efficient palliative care model for ventricular assist devices. J Palliat Med 2016;19:1312–1315.
64. Lakin JR, Koritsanszky LA, Cunningham R, et al. A systematic intervention to improve serious illness communication in primary care. Health Aff (Millwood) 2017;36:1258–1264.
65. Metzger M, Song MK, Ward S, et al. A randomized controlled pilot trial to improve advance care planning for LVAD patients and their surrogates. Heart Lung 2016;45:186–192.
66. Metzger M, Song MK, Devane-Johnson S. LVAD patients' and surrogates' perspectives on SPIRIT-HF: An advance care planning discussion. Heart Lung 2016;45:305–310.
67. Song M-K, Ward SE, Happ MB, et al. Randomized controlled trial of SPIRIT: An effective approach to preparing African American dialysis patients and families for end of life. Res Nurs Health 2009;32:260–273.
68. Song MK, Ward SE, Fine JP, et al. Advance care planning and end-of-life decision making in dialysis: A randomized controlled trial targeting patients and their surrogates. Am J Kidney Dis 2015;66:813–822.
69. Song MK, Metzger M, Ward SE. Process and impact of an advance care planning intervention evaluated by bereaved surrogate decision-makers of dialysis patients. Palliat Med 2017;31:267–274.
70. Stein RA, Sharpe L, Bell ML, et al. Randomized controlled trial of a structured intervention to facilitate end-of-life decision making in patients with advanced cancer. J Clin Oncol 2013;31:3403–3410.
71. Stanford J, Sandberg DM, Gwyther L, Harding R. Conversations worth having: The perceived relevance of advance care planning among teachers, hospice staff, and pastors in Knysna, South Africa. J Palliat Med 2013;16:762–767.
72. Huang C-HS, Crowther M, Allen RS, et al. A pilot feasibility intervention to increase advance care planning among African Americans in the deep south. J Palliat Med 2016;19:164–173.
73. Karel MJ, Powell J, Cantor MD. Using a Values Discussion Guide to facilitate communication in advance care planning. Patient Educ Couns 2004;55:22–31.
74. Smith SL. Advance care planning communication for young adults: A role for simulated learning. J Hosp Palliat Nurs 2017;19:460–467.
75. Kazmerski T, Weiner D, Schachner D, et al. Advance care planning in pediatric Cf patients: A quality improvement project. Pediatr Pulmonol 2015;50:446.
76. Song MK, Ward SE, Lin FC, et al. Racial differences in outcomes of an advance care planning intervention for dialysis patients and their surrogates. J Palliat Med 2016;19:134–142.
77. Davison SN. Advance care planning in patients with chronic kidney disease. Semin Dial 2012;25:657–663.
78. Davison SN, Torgunrud C. The creation of an advance care planning process for patients with ESRD. Am J Kidney Dis 2007;49:27–36.
79. Mahon MM. An advance directive in two questions. J Pain Symptom Manage 2011;41:801–807.
80. Pearce J, Ridley J. Communication in life-limiting illness: A practical guide for physicians. B C Med J 2016;58:262–267.
81. Dallas RH, Wilkins ML, Wang J, et al. Longitudinal pediatric palliative care: Quality of life & Spiritual Struggle (FACE): Design and methods. Contemp Clin Trials 2012;33:1033–1043.
82. Kimmel AL, Wang J, Scott RK, et al. FAmily CEntered (FACE) advance care planning: Study design and methods for a patient-centered communication and decision-making intervention for patients with HIV/AIDS and their surrogate decision-makers. Contemp Clin Trials 2015;43:172–178.
83. Curtin KB, Watson AE, Wang J, et al. Pediatric advance care planning (pACP) for teens with cancer and their families: Design of a dyadic, longitudinal RCCT. Contemp Clin Trials 2017;62:121–129.
84. Piamjariyakul U, Myers S, Werkowitch M, Smith CE. End-of-life preferences and presence of advance directives among ethnic populations with severe chronic cardiovascular illnesses. Eur J Cardiovasc Nurs 2014;13:185–189.
85. Norlander L, McSteen K. The kitchen table discussion: A creative way to discuss end-of-life issues. Home Healthc Nurse 2000;18:532–540.
86. Briggs L. Shifting the focus of advance care planning: Using an in-depth interview to build and strengthen relationships. J Palliat Med 2004;7:341–349.
87. Korfage IJ, Rietjens JAC, Overbeek A, et al. A cluster randomized controlled trial on the effects and costs of advance care planning in elderly care: Study protocol. BMC Geriatr 2015;15:87.
88. Rietjens JA, Korfage IJ, Dunleavy L, et al. Advance care planning—a multi-centre cluster randomised clinical trial: The research protocol of the ACTION study. BMC Cancer 2016;16:264.
89. Malhotra C, Sim DKL, Jaufeerally F, et al. Impact of advance care planning on the care of patients with heart failure: Study protocol for a randomized controlled trial. Trials 2016;17:285.
90. der Schmitten J, Rotharmel S, Mellert C, et al. A complex regional intervention to implement advance care planning in one town's nursing homes: Protocol of a controlled inter-regional study. BMC Health Serv Res 2011;11:14.
91. Bernacki R, Hutchings M, Vick J, et al. Development of the serious illness care program: A randomised controlled trial of a palliative care communication intervention. BMJ Open 2015;5:e009032.
92. Song MK, Ward SE. Making visible a theory-guided advance care planning intervention. J Nurs Scholarsh 2015;47:389–396.
93. Song MK, Unruh ML, Manatunga A, et al. SPIRIT trial: A phase III pragmatic trial of an advance care planning intervention in ESRD. Contemp Clin Trials 2018;64:188–194.
94. Prommer EE. Using the values-based history to fine-tune advance care planning for oncology patients. J Cancer Educ 2010;25:66–69.
95. Zadeh S, Pao M, Wiener L. Opening end-of-life discussions: How to introduce Voicing My CHOiCES$^{\text{TM}}$, an advance care planning guide for adolescents and young adults. Palliat Support Care 2015;13:591–599.
96. Balaban RB. A physician's guide to talking about end-of-life care. J Gen Intern Med 2000;15:195–200.

97. Donovan HS, Ward SE, Song MK, et al. An update on the representational approach to patient education. J Nurs Scholarsh 2007;39:259–265.
98. Lewin S, Hendry M, Chandler J, et al. Assessing the complexity of interventions within systematic reviews: Development, content and use of a new tool (iCAT _ SR). BMC Med Res Methodol 2017;17:1–13.
99. Hoffmann TC, Oxman AD, Ioannidis JPA, et al. Enhancing the usability of systematic reviews by improving the consideration and description of interventions. BMJ 2017;358:j2998.
100. Sudore RL, Lum HD, You JJ, et al. Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. J Pain Symptom Manage 2017;53:821–832.e1.
101. Tulsky JA, Beach MC, Butow PN, et al. A research agenda for communication between health care professionals and patients living with serious illness. JAMA Intern Med 2017;177:1361–1366.
102. Scherrens AL, Beernaert K, Robijn L, et al. The use of behavioural theories in end-of-life care research: A systematic review. Palliat Med 2018;32:1055–1077.
103. Sudore RL, Knight SJ, McMahan RD, et al. A novel website to prepare diverse older adults for decision making and advance care planning: A pilot study. J Pain Symptom Manage 2014;47:674–686.
104. Masters S, Gordon J, Whitehead C, et al. Coaching older adults and carers to have their preferences heard (COACH): A randomised controlled trial in an intermediate care setting (study protocol). Australas Med J 2012;5:444–454.
105. Green MJ, Levi BH. Development of an interactive computer program for advance care planning. Health Expect 2009;12:60–69.