Update in Hospice and Palliative Care

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Abstract

Objective: The objective of this update, presented at the 2018 Annual Assembly of the American Association of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA), is to identify, summarize, and critique a sampling of recent research that has the potential for marked impact on hospice and palliative clinical practice.

Methods: In a departure from previous years, we surveyed AAHPM and HPNA members to determine focused topic areas, from which we selected candidate articles. The two topic areas selected by the membership were “Moving into the great beyond: bringing palliative care into the subspecialties” and “Improving the conversation for patients with serious illness.” Seven reports of original research published between January 1, 2012 and November 3, 2017 were identified through a systematic search of relevant databases, hand searching of leading journals, and discussion with experts in the field. Candidate articles were scored and ranked independently by four reviewers based on methodological quality, appeal to a breadth of palliative care clinicians across settings, and potential for impact.

Results: We summarize the seven articles with the highest ratings.

Keywords: hospice clinical care; palliative clinical care; state of science; update in hospice care; update in palliative care

Introduction

THE OBJECTIVE OF THIS UPDATE, presented at the 2018 Annual Assembly of the American Association of Hospice and Palliative Medicine (AAHPM) and the Hospice and Palliative Nurses Association (HPNA), is to identify, summarize, and critique a sampling of research from the prior five years (2012–2017) that has the potential for marked impact on hospice and palliative clinical practice.

In a departure from previous years, we surveyed AAHPM and HPNA members to determine focused topic areas, from which we selected candidate articles. First, we identified 10 topic areas from the most clicked AAHPM Hospice and Palliative Medicine SmartBriefs from June 1, 2016 to July 30, 2017. Based on feedback from State of the Science alumni, we narrowed down the top 10 topics to the following 4 topics: (1) *Considering the caregiver in palliative care and hospice*; (2) *Improving the conversation for patients with serious illness*;

upstream and downstream, younger and older; (3) *Health care spending: how to decrease the burden for patients with serious illness and their caregivers*; and (4) *Moving into the great beyond: bringing palliative care into the subspecialties*. Next, we surveyed the AAHPM and HPNA membership and asked the respondents to rank the four topics based on the level of interest.

The two topics with the most votes were “Moving into the great beyond: bringing palliative care into the subspecialties” and “Improving the conversation for patients with serious illness.” A comprehensive literature search was performed by K.D. in November 2017 for each of these two topic areas (Supplementary Appendix). Relevant publications were identified by searching the following databases: MEDLINE (through Ovid MEDLINE [1946-present], Ovid MEDLINE Epub Ahead of Print, In-Process and Other Non-Indexed Citations, and Ovid MEDLINE Daily), CINAHL (Cumulative Index to Nursing and Allied Health Literature through EBSCOhost), Web of Science Core Collection (through Thomson Reuters, including Science

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Citation Index Expanded 1974 to present, and Social Sciences Citation Index 1974 to present), Cochrane Library (through Wiley, including Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effect, Cochrane Central Register of Controlled Trials, Cochrane Methodology Register, Health Technology Assessment Database, and NHS Economic Evaluation Database, 1992 to present), and PsycINFO (through Ovid, 1806 to October week 4 2017). Limiters were used for English language and publication date since 2012. This was supplemented by hand searching of leading journals and discussion with experts in the field.

Candidate articles were scored and ranked independently by four reviewers based on methodological quality, appeal to a breadth of palliative care clinicians across settings, and potential for impact. We summarize the seven articles with the highest ratings.

Moving into the Great Beyond: Bringing Palliative Care into the Subspecialties

Effect of inpatient palliative care on quality of life 2 weeks after hematopoietic stem cell transplantation: A randomized clinical trial¹

Effect of inpatient palliative care during hematopoietic stem-cell transplant on psychological distress 6 months after transplant: Results of a randomized clinical trial²

High-dose chemotherapy followed by hematopoietic stem cell transplant (HCT) is curative for many with hematologic malignancies but incurs substantial symptom burden and is associated with long-term psychological morbidity.³⁻⁵ The authors conducted a randomized controlled trial (RCT) to examine the impact of inpatient palliative care during hospital admission for HCT on the primary outcome of quality of life (Functional Assessment of Cancer Therapy-Bone Marrow Transplant [FACT-BMT]) two weeks after admission for HCT.

In a series of additional analyses, reported in the two aforementioned articles, they examined the effect on (1) symptoms (Edmonton Symptom Assessment Scale [ESAS]), fatigue (Functional Assessment of Cancer Therapy-Fatigue subscale), and mood (Hospital Anxiety and Depression Scale, [HADS], and Patient Health Questionnaire, [PHQ]-9) during week 2 of hospitalization for HCT; (2) quality of life, symptoms, fatigue, mood, and post-traumatic stress disorder (PTSD) symptoms (PTSD Checklist-Civilian version) at three months; (3) quality of life, mood, and PTSD symptoms six months after HCT; and (4) caregiver quality of life and mood during week 2 of hospitalization.

One hundred sixty of 186 potentially eligible participants at a single site were randomized to intervention ($n=81$) or standard care ($n=79$). Eligible patients were >18 years of age, English speaking, and undergoing inpatient HCT for a hematologic malignancy. Patients were excluded if they had previously undergone HCT. Intervention participants met the specialty-trained physician (MD) or nurse practitioner (NP) within 72 hours of assignment and were seen twice weekly during admission. Usual care (UC) participants received standard oncological care.

Compared with UC, those in the intervention arm reported improved quality of life, symptom burden, fatigue, depression, and anxiety symptoms at week 2 of hospitalization in models adjusted for baseline scores. At three months, inter-

vention participants continued to report better quality of life, lower depression, and additionally lower symptoms of PTSD, but no difference in symptoms, anxiety, or fatigue. At six months, the impact on depression and PTSD symptoms persisted, although there was no longer a difference in quality of life. In mediation analyses, the effect on depression and PTSD symptoms at six months was partly mediated by anxiety and physical symptoms during hospitalization. There was no significant difference in caregivers' quality of life, but caregivers of intervention participants reported lower depression symptoms during week 2 of hospitalization.

Study appraisal

This was a high-quality randomized clinical trial and the first to examine the impact of palliative care on outcomes for patients undergoing HCT. Strengths included randomization and allocation concealment; reliable, valid, and clinically meaningful outcome measures; low attrition and sensitivity analyses to account for missing data; and mediation analyses to determine mechanism of intervention's effect. Clear reporting of processes of care (e.g., intervention dose and nature) will enable replication and evaluation in other settings. The use of an attention control and reporting additional potential confounders (e.g., graft versus host disease [GvHD]) would have further strengthened confidence in ascribing outcomes to the intervention. The limited racial and ethnic diversity of the sample limits generalizability. Analysis of prespecified cost and survival outcomes will further inform dissemination.

Clinical bottom line

Concurrent inpatient palliative care during HCT improved quality of life, symptoms, and mood at week 2 of HCT hospitalization and symptoms of depression and PTSD six months after HCT.

The palliative care in heart failure (PAL-HF) randomized controlled clinical trial⁶

Heart failure (HF) in the advanced stages is characterized by high morbidity and mortality and is the most common cause of hospitalization for Medicare recipients; yet, there are few studies on the effectiveness of palliative care integrated into HF care.^{7,8} The authors report the results of a single-center RCT comparing the effect of an NP-led palliative care intervention (palliative care in HF [PAL-HF]+UC) with UC on quality of life (primary outcome) and depression, anxiety, and spiritual well-being (secondary outcomes) in patients with advanced HF.

One hundred fifty-one patients at high risk of readmission or mortality were enrolled at a single academic center during or shortly after hospital admission for HF. Exclusion criteria included anticipated ventricular assist device placement or heart transplant, renal replacement therapy, or nonterminal cardiac illness. UC participants were managed by a cardiologist-directed team only. Intervention participants were followed by a specialty trained-palliative care NP in the outpatient setting for six months.

The intervention focused on assessing and managing the multiple domains of quality of life for patients with advanced HF, including physical symptoms, psychosocial concerns, spiritual concerns, and advance care planning (ACP), using structured assessments and standardized treatment algorithms.

Quality of life was measured by Functional Assessment of Chronic Illness Therapy-Palliative Care scale (FACIT-Pal) and Kansas City Cardiomyopathy Score (KCCQ). Depression and anxiety were measured using HADS and spiritual well-being measured using Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being scale (FACIT-Sp). Treatment effect was evaluated six months postrandomization using linear mixed models.

Patients in the intervention arm had a statistically and clinically significant greater increase in quality of life for six months by both quality of life measures (FACIT-Pal: +11.77-point difference, $p=0.030$; KCCQ: +9.49-point difference, $p=0.035$). PAL-HF+UC participants reported significantly greater improvement in depression, anxiety, and spiritual well-being compared with UC participants. There was no difference between groups in rehospitalizations; however, this did not clearly account for right censoring (i.e., subjects leaving the study within six months before hospitalization occurred). There was no difference in the mortality between the two groups at six months.

Study appraisal

This study addressed an important question: does integrated concurrent palliative care improve outcomes for high mortality risk patients with advanced HF? This study had the largest participant sample of any HF palliative care trial to date. Loss to follow-up (12%) and mortality (29%) was fairly balanced; however, strategies to address missing data would have helped assure unbiased estimates of effect. Clear reporting of any central randomization and allocation concealment and the use of independent blinded outcome assessors would have further strengthened confidence in the results. Going forward, a comprehensive cost and utilization analysis will inform the scaling for this intervention. The sample was racially diverse; however, lack of data on refusals and restriction to a single academic center limits conclusions about generalizability.

Clinical bottom line

An NP-led outpatient palliative care intervention plus usual cardiologist-directed care improved quality of life, depression, anxiety, and spiritual well-being in patients with advanced HF after hospitalization for HF. Replication of findings in a multicenter study is needed to inform future dissemination.

Survival, Healthcare utilization, and end-of-life care among older adults with malignancy-associated bowel obstruction: Comparative study of surgery, venting gastrostomy, or medical management⁹

Malignancy-associated bowel obstruction (MBO) is a common complication of gastrointestinal and gynecological malignancies, incurs considerable symptom burden, and is associated with high mortality.^{10–12} Palliative management includes medical, surgical treatment, or venting gastrostomy (VGT), but clinical decision making lacks data to help discern the most appropriate treatment for patients at the end of life.

In this retrospective cohort study, the authors used data from the Surveillance, Epidemiology and End Results Medicare claims database to examine the association between MBO treatment modalities (medical treatment vs. surgical treatment

vs. VGT) and outcomes of overall survival, hospital readmissions, and health care use at the end of life.

Among 3583 Medicare beneficiaries hospitalized for MBO after a diagnosis of stage IV ovarian or pancreatic cancer, mortality at 30, 90, and 180 days after first admission was 29%, 53%, and 65%, respectively. Surgery was associated with a lower risk of death (adjusted hazard ratio 0.84, [0.77–0.91], $p<0.001$) and VGT an increased risk of death (adjusted hazard ratio 1.86, [1.62–2.12], $p<0.001$) than medical management. In those discharged alive after the first admission for MBO ($n=3135$), 29% had a subsequent readmission for MBO. Surgery and VGT were both associated with a lower risk of readmission than medical management (adjusted subdistribution hazard ratios: surgery 0.69 (0.59–0.80), $p<0.001$; VGT 0.41 (0.23–0.58), $p<0.001$). In those who died during the study period ($n=3279$), surgery was associated with less hospice enrollment and increased likelihood of ICU admission at the end of life compared with medical management. Conversely, VGT was associated with increased hospice enrollment and reduced likelihood of ICU admission at the end of life compared with medical management.

Study appraisal

This was a large claims-based retrospective analysis that characterized survival, readmission, and intensity of end-of-life care after hospitalization for MBO in a sample of Medicare beneficiaries. There were some limitations. In the absence of random assignment, factors influencing treatment selection (e.g., frailty), rather than the treatment itself, could explain the findings. Because this is a claims-based study, there is little detail on the specifics of the different treatment modalities and the sample was restricted to people with stage IV pancreatic/ovarian cancer and Medicare fee for service enrollment.

Clinical bottom line

In patients with stage IV ovarian and pancreatic cancers hospitalized for MBO, compared with medical management, VGT is associated with a higher mortality but lower risk of readmission and lower intensity end-of-life care. Compared with medical management, surgery is associated with a lower mortality, lower risk of readmission, but higher intensity end-of-life care. These findings can help better inform collaborative decision making around the management of malignant bowel obstruction at the end of life.

Improving the Conversation for Patients with Serious Illness

Effects of the goals of care intervention for advanced dementia: A randomized clinical trial¹³

More than five million Americans have dementia, many in the advanced stage.¹⁴ Decision aids can facilitate shared decision making, but few are tailored to the needs of family decision makers of patients with advanced dementia. In this cluster RCT, investigators evaluated the efficacy of a goals of care decision aid together with a structured care planning meeting on quality of communication (QOC) and palliative care in nursing home residents with advanced dementia.

Twenty-two nursing homes were randomized at the level of the site (11 sites representing 151 dyads in each arm). The

multicomponent intervention comprised (1) a video decision aid and guide for family decision makers, (2) a staff communication training session, and (3) a structured care planning meeting. The attention control comprised (1) a video for family decision makers on communicating in dementia, (2) a video on study processes for staff, and (3) a UC planning meeting.

Primary outcomes at three months were (1) family-rated QOC (QOC questionnaire—overall, general communication subscale, and end-of-life care subscale, all scored 0–10), (2) family report of concordance with clinicians on primary goal of care (prolonging life, supporting function, and improving comfort), and (3) family report of treatment consistent with preferences (measured using the ACP score). Secondary outcomes, reported at six and nine months or death, were (1) family-rated symptoms (Symptom Management at the End of Life in Dementia Scale), (2) family satisfaction with care (Satisfaction with Care at the End of Life in Dementia), and (3) palliative care content of treatment plans (Palliative Care Domain Score). Primary and secondary outcomes were analyzed using generalized mixed effect models to account for clustering of residents within nursing home and repeated measures. In addition, impact on Medical Orders for Scope of Treatment (MOST) completion and hospital transfers was reported.

QOC was significantly better in the intervention arm than attention control at three months (overall: 6.0 vs. 5.6, $p=0.05$; end-of-life subscale: 3.7 vs. 3.0 $p=0.02$). There was no difference in goal concordance at three months (77.2% vs. 70.1%, $p=0.12$) but at nine months or death, intervention participants had greater goal concordance (88.4% vs. 71.2%, $p=0.001$). Treatment consistent with preferences (defined as proportion with one or more unfavorable responses from three items on the ACP score) did not differ between arms. Residents at intervention sites had higher palliative care content in treatment plans at six months, especially goals of care documentation (91% vs. 42%, $p<0.001$), but there was no difference in symptoms or satisfaction with care at any time point. At nine months or death, MOST completion in intervention participants was higher than control (35% vs. 16%, $p=0.05$). Hospital transfers were half as frequent at intervention sites versus control (0.08 per 90 person-days vs. 0.16 per 90 person-days, $p=0.02$). There was no significant difference in survival time from enrollment between arms.

Study appraisal

This was a well-designed multisite cluster RCT. Particular strengths included use of an attention control and fidelity to intervention assured through monitoring and retraining of nursing home sites as necessary. Generalizability to other nursing homes is supported by recruitment of multiple sites with diverse characteristics although within one state, North Carolina. At the dyad level, restriction of eligibility to long-stay residents and a high refusal rate (38% of eligible dyads) impacts the ability to generalize; reasons for refusal were not reported. Although promising, results suggest potential for further improvement in target outcomes—results of analysis of moderators and mediators of the intervention's effect will inform future interventions.

Clinical bottom line

A goals of care decision aid and structured care plan meeting for family decision makers can improve QOC, documentation of care preferences, and reduce hospital

transfers in nursing home residents with advanced dementia, with no impact on survival.

Advance care planning and end-of-life decision making in dialysis: A randomized controlled trial targeting patients and their surrogates.¹⁵

End-stage renal disease (ESRD) is highly prevalent and the mortality rate of patients receiving dialysis can exceed that for most types of cancer.¹⁶ Timely discussions with patients with ESRD to establish their goals of care are recommended; however, discussions often focus narrowly on advance directives (ADs) or occur close to death. The authors developed Sharing Patient's Illness Representations to Increase Trust (SPIRIT), a nurse-led psychoeducational intervention for patients with ESRD receiving hemodialysis that aims to help patients clarify their preferences for end-of-life care, aid surrogates in better understanding patients' wishes, and prepare surrogates for their role. In this multicenter RCT, the investigators evaluated the intervention's impact on end-of-life care decision making and surrogate bereavement outcomes.

Eligible dyads, recruited from 20 community dialysis centers, were randomized to the nurse-led SPIRIT intervention ($n=109$) or UC ($n=101$). Intervention participants received the SPIRIT intervention for two sessions in addition to UC; UC participants received (1) written information about ADs, (2) encouragement by a social worker to complete an AD, and (3) a review of resuscitation preferences with the medical team. Primary outcomes included dyad congruence around patient goals of care (based on two hypothetical clinical scenarios), patient decisional conflict (patient decisional conflict scale range 1–5, higher scores correlating with greater conflict), and surrogate decision-making confidence (scale range 1–4, higher scores correspond with greater confidence). Bereavement outcomes included anxiety and depression (HADS) and post-traumatic stress symptoms (Post-Traumatic Symptoms Scale 10). Of the 210 dyads, 173 dyads (82%) completed 12 months follow-up. Using generalized estimating equation models, dyad congruence was better in intervention versus UC participants at 2 months (odds ratio [OR]: 1.9, 1.1–3.3, $p=0.03$) but not at 6, 12 months, or the overall 12-month time period.

Patient decisional conflict was significantly lower in intervention versus UC participants for 12 months ($\beta=-0.12$, -0.22 to 0.02 , $p=0.01$). Surrogate decision-making confidence was greater in intervention than UC participants at 2 months ($\beta=0.12$, -0.002 to 0.23 , $p=0.05$), but not at 6 and 12 months or the overall 12-month time period. Effect of SPIRIT on dyad congruence decreased over time; in adjusted models, the impact on dyad congruence was significant. In the subgroup of the 45 surrogates whose loved one died, surrogates who received SPIRIT had significantly less anxiety, depression, and post-traumatic symptoms in the six months after death of their loved one.

Study appraisal

This was a high-quality multicenter RCT that demonstrated the promising impact of the SPIRIT intervention on dyadic congruence, patient decisional conflict, surrogate decision-making confidence, and surrogate bereavement outcomes. The effect of SPIRIT on dyadic congruence waned over time and may suggest the need for supplemental sessions. Overall, the magnitude of effect, especially on decision-making conflict

and surrogate decision-making confidence, was small. Notably, at baseline patients reported low decisional conflict and surrogates had high confidence; the impact of SPIRIT may be more evident in populations with higher needs at baseline. The study was conducted in one U.S. region and less than half of the eligible dyads enrolled, potentially affecting generalizability; furthermore, characteristics of patients who refused (and whether they differ from enrollees) were not reported.

Clinical bottom line

A nurse-led ACP psychoeducational intervention was associated with improvements in patient and surrogate preparedness for end-of-life decision making, surrogate decision-making confidence, and bereavement outcomes.

Effect of the PREPARE website versus an easy-to-read Advance Directive on Advance Care Planning documentation and engagement among veterans: A randomized clinic trial¹⁷

ACP is the process through which individuals identify and communicate goals for future medical care and complete ADs.¹⁸ To prepare individuals to engage in ACP, the authors developed PREPARE (prepareforyourcare.org), an easy-to-read culturally appropriate website. This randomized comparative effectiveness trial, conducted in multiple Veteran Affairs outpatient clinics, examined the effect of PREPARE plus an easy-to-read AD versus AD alone on ACP completion and ACP engagement.

Inclusion criteria included patients with two or more chronic illnesses and upcoming primary care appointment. Four hundred fourteen eligible participants were randomized to PREPARE+AD ($n=205$) or AD alone ($n=209$). Participants in the AD only arm reviewed the easy-to-read print AD. Participants in the intervention arm reviewed the PREPARE website, received a “Summary of My Wishes” generated by the website, an action plan document, and the easy-to-read print AD. Participants in both arms received a call before their clinic visit, during which intervention arm participants were reminded to bring their documents. No clinician or systems changes were implemented. ACP documentation, including legal forms or documented discussions, was assessed through electronic medical review at nine months.

New ACP documentation within nine months of enrollment was higher in intervention group than control group (35% vs. 25%, adjusted OR: 1.61; 95% confidence interval: 1.03–2.51, $p=0.04$), and this effect did not differ by age, gender, race/ethnicity, health status, health literacy, prior ACP documentation, or presence of a surrogate decision maker. ACP engagement was measured by an ACP engagement survey. This questionnaire includes both process measures of knowledge, contemplation, self-efficacy, and readiness, assessed on an average 5-point Likert scale, and action measures, such as discussing and documenting wishes using “yes” or “no” response options on a 0- to 25-point scale. For six months, the intervention group had significantly greater increase in ACP engagement than the control group.

Study appraisal

In this high-quality RCT, the randomization process resulted in well-balanced groups at baseline. Blinding of outcome assessors was thorough and missing data minimal. Time between

receipt of PREPARE and AD or AD alone and primary care visit was not reported, and it would have been beneficial to know this was balanced. The vast majority of respondents were male as this was conducted at the Veterans Affairs (VA). Otherwise, the sample was socioeconomically diverse and the intervention’s effect did not differ by race/ethnicity or health literacy, underscoring the broad generalizability of the findings. On average, participants rated their health as good and above supporting the idea of PREPARE as a component of upstream ACP.

Notably, only 44% of eligible participants consented to enrollment. Although refusers did not differ from enrollees in terms of race/ethnicity or gender, there may be other important differences, such as attitudes toward ACP, that limit generalizability of the results from the subsample to the broader target population. Even though the intervention did not include clinician-level changes, only two clinicians refused to participate suggesting potential high clinician support for ACP; effectiveness may differ in areas with lower clinician support. Understanding the mechanism of PREPARE’s effect and the patient–clinician and system-level moderators of its impact will inform its role as part of a multicomponent intervention.

Clinical bottom line

In a sample of older veterans with multiple chronic illnesses, PREPARE increased AD completion and ACP engagement over and above an easy-to-read print AD alone in the absence of clinician- or system-level interventions.

A randomized clinical trial of adolescents with HIV/AIDS: Pediatric advance care planning¹⁹

In the United States, 11,000 adolescents have been diagnosed with AIDS from the beginning of the epidemic to 2016.²⁰ Despite improvements in life expectancy, complications can arise at any time underscoring the importance of engaging adolescents with HIV/AIDS and their legal guardians/surrogates in ACP. In this multisite RCT, the authors examined the effect of an ACP intervention, compared with active control, on adolescent/surrogate decision-maker congruence in treatment preferences.

Patient eligibility criteria included age 14–21 years with HIV/AIDS, English speaking, awareness of diagnosis, no severe depression/suicidal ideation/psychosis, no developmental delay or HIV-related dementia, and presence of legal guardian or chosen surrogate decision maker. Surrogate decision makers were eligible if they were ≥ 18 years of age. Eligible dyads were enrolled (105 enrolled of the 203 eligible) from six pediatric outpatient HIV clinics. Dyads were randomized to intervention ($n=54$) or control ($n=51$).

The three-part intervention (delivered in three weekly sessions) comprised (1) a survey-based assessment of values, beliefs, life experience with illness and end-of-life care (Lyon Family-Centered ACP Survey); (2) a structured ACP interview with dyad incorporating Statement of Treatment Preferences, used to encourage dialogue around preferences for treatment in three clinical situations; and (3) AD completion (Five Wishes document). Sessions were delivered by non-clinician case managers, registered nurses, social workers, or psychologists. Dyads in the active control arm had three 60 minute weekly sessions with the trained research assistant: (1) assessment of developmental history, (2) safety session, and (3) session on nutrition and exercise.

The primary outcome was dyad congruence, measured immediately after intervention/active control (session 2), and at three months after enrollment. To assess dyad congruence, patients and their legal guardians/surrogates were presented with the same three hypothetical clinical scenarios on the Statement of Treatment Preferences. The clinical scenarios were (1) long hospital stay with many treatments and low chance of survival, (2) functional impairment requiring 24-hour care and high chance of survival, and (3) mental impairment requiring 24-hour nursing care and high chance of survival. Then, the patient and the legal guardian/surrogate were asked to indicate the adolescent's preferences from one of three categories: (1) continue all treatments, (2) focus on quality of life, or (3) do not know. Congruence was reported as prevalence- and bias-adjusted kappa statistic.

In intervention dyads, congruence of treatment preferences immediately postintervention indicated substantial agreement in all three hypothetical treatment scenarios; at the same time point in control participants, congruence for two scenarios was fair and for the third (functional impairment) nil. After three months, in intervention dyads, congruence for all three scenarios was lower than immediately postintervention, moderate agreement for two scenarios, and fair for the third (functional impairment). Congruence in control arm remained low.

Study appraisal

This multisite RCT, which is the first ACP trial conducted in this population, demonstrated the promising impact of an ACP intervention on dyad congruence around end-of-life treatment preferences. Groups were well balanced at baseline, consistent with good randomization. Blinding of research assistants reduced bias. Use of active control was well considered and accounted for nonspecific effects of attention rather than the intervention itself. Enrollment of a diverse sample of patients from a number of clinics increases generalizability of the findings. Limitations include analysis on basis of treatment received rather than that assigned through randomization. In addition, the number of hypothetical clinical scenarios (3) and options (3) used to assess dyad congruence may be a limited reflection of the complexity of the realities of decision making. Future studies should examine impact on a broader range of outcomes.

Clinical bottom line

In a sample of dyads of adolescents with HIV/AIDS and their legal guardian/surrogate decision makers, a structured ACP intervention, using trained facilitators, increased dyadic decisional congruence in hypothetical scenarios compared with active control.

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References

1. El-Jawahri A, LeBlanc T, VanDusen H, et al.: Effect of inpatient palliative care on quality of life 2 weeks after hematopoietic stem cell transplantation: A randomized clinical trial. *JAMA* 2016;316:2094–2103.
2. El-Jawahri A, Traeger L, Greer JA, et al.: Effect of inpatient palliative care during hematopoietic stem-cell transplant on psychological distress 6 months after transplant: Results of a randomized clinical trial. *J Clin Oncol* 2017; 35:3714–3721.
3. McQuellon RP, Russell GB, Rambo TD, et al.: Quality of life and psychological distress of bone marrow transplant recipients: The “time trajectory” to recovery over the first year. *Bone Marrow Transplant* 1998;21:477–486.
4. Prieto JM, Atala J, Blanch J, et al.: Patient-rated emotional and physical functioning among hematologic cancer patients during hospitalization for stem-cell transplantation. *Bone Marrow Transplant* 2005;35:307–314.
5. El-Jawahri AR, Traeger LN, Kuzmuk K, et al.: Quality of life and mood of patients and family caregivers during hospitalization for hematopoietic stem cell transplantation. *Cancer* 2015;121:951–959.
6. Rogers JG, Patel CB, Mentz RJ, et al.: Palliative care in heart failure: The PAL-HF randomized, controlled clinical trial. *J Am Coll Cardiol* 2017;70:331–341.
7. Gelfman LP, Bakitas M, Warner Stevenson L, et al.: The state of science on integrating palliative care in heart failure. *J Palliat Med* 2017;20:592–603.
8. Khan RF, Feder S, Goldstein NE et al.: Symptom burden among patients who were hospitalized for heart failure. *JAMA Intern Med* 2015;175:1713–1715.
9. Lilley EJ, Scott JW, Goldberg JE, et al.: Survival, health-care utilization, and end-of-life care among older adults with malignancy-associated bowel obstruction: Comparative study of surgery, venting gastrostomy, or medical management. *Ann Surg* 2018;267:692–699.
10. Tuca A, Guell E, Martinez-Losada E, et al.: Malignant bowel obstruction in advanced cancer patients: Epidemiology, management, and factors influencing spontaneous resolution. *Cancer Manag Res* 2012;4:159–169.
11. Chakraborty A, Selby D, Gardiner K, et al.: Malignant bowel obstruction: Natural history of a heterogeneous patient population followed prospectively over two years. *J Pain Symptom Manage* 2011;41:412–420.
12. Alese OB, Kim S, Chen Z, et al.: Management patterns and predictors of mortality among US patients with cancer hospitalized for malignant bowel obstruction. *Cancer* 2015; 121:1772–1778.
13. Hanson LC, Zimmerman S, Song MK, et al. Effect of the goals of care intervention for advanced dementia: A randomized clinical trial. *JAMA Intern Med* 2017;177:24–31.
14. Mitchell SL, Black BS, Ersek M, et al. Advanced dementia: State of the art and priorities for the next decade. *Ann Intern Med* 2012;156 (1 Pt 1):45–51.
15. 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.
16. Saeed F, Arrigain S, Schold JD, et al.: What are the risk factors for one-year mortality in older patients with chronic kidney disease? An analysis of the Cleveland clinic CKD registry. *Nephron* 2018;21:1–7.
17. Sudore RL, Boscardin J, Feuz MA, et al.: Effect of the PREPARE website vs an easy-to-read advance directive on

- advance care planning documentation and engagement among veterans: A randomized clinical trial. *JAMA Intern Med* 2017;177:1102–1109.
18. Sudore R, Lum H, You J, et al.: Define advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. *J Pain Symptom Manage* 2017; 53:821–832.
 19. 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.
 20. Centers for Disease Control and Prevention: HIV Surveillance Report, 2016; vol. 28. [www.cdc.gov/hiv/library/](http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html)

[reports/hiv-surveillance.html](http://www.cdc.gov/hiv/library/reports/hiv-surveillance.html). Published November 2017. (Last accessed May 12, 2018).

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