UCSF

UC San Francisco Previously Published Works

Title

Empowering Patient Participation in Advance Care Planning Discussions: Audio Recordings of Primary Care Visits Among PREPARE Randomized Trial Participants (CS201B)

Permalink

https://escholarship.org/uc/item/6564160h

Journal

Journal of Pain and Symptom Management, 60(1)

ISSN

0885-3924

Authors

Freytag, Jennifer Barnes, Deborah Shi, Ying et al.

Publication Date

2020-07-01

DOI

10.1016/j.jpainsymman.2020.04.037

Peer reviewed

(all p \leq .001). Specifically, morphine dose decreased from 45.0 mg in 2010 to 34.3 mg in 2018 for cancer patients and from 16.0 mg in 2010 to 12.0 mg in 2018 for non-cancer patients. The proportion with frequent, uncontrolled pain at the end of life increased from 51.8% in 2010 to 57.3% in 2018 for cancer patients and from 44.6% in 2010 to 47.5% in 2018 for non-cancer patients. These differences persisted after adjustment for patient characteristics.

Conclusion(s). Decreases in opioid prescribing among patients near the end of life over the last decade have been accompanied by increases in uncontrolled pain.

Impact. Our findings highlight potential unintended consequences of initiatives to improve the appropriateness and safety of opioid prescribing, and profile the potential impact on Veterans, a particularly vulnerable patient population.

Oral Concurrent Sessions

Effects of Early Palliative Care for Family Caregivers of Persons with Advanced Heart Failure: The ENABLE CHF-PC Randomized Controlled Trial (CS201A)



Deborah Ejem, PhD MA, University of Alabama at Birmingham. Rachel Wells, PhD RN CNL, University of Alabama at Birmingham. Andres Azuero, PhD, University of Alabama at Birmingham. Macy Stockdill, RN, University of Alabama at Birmingham. Konda Keebler, DNP, University of Alabama at Birmingham. Elizabeth Sockwell, MSN, University of Alabama at Birmingham Hospital. Sheri Tims, BSN RN CHPN, University of Alabama at Birmingham. Sally Engler, MPH, University of Alabama at Birmingham. Elizabeth Kvale, MD MSPH FAAHPM, Dell Medical School, University of Texas. Rodney Tucker, MD MMM FAAHPM, University of Alabama at Birmingham. Kathryn Burgio, PhD, University of Alabama at Birmingham and Birmingham VA Medical Center. Jose Tallaj, MD, University of Alabama at Birmingham. Keith Swetz, MD MA HMDC FACP FAAHPM, University of Alabama at Birmingham. James Dionne-Odom, PhD RN ACHPN, University of Alabama at Birmingham. Marie Bakitas, PhD CRNP FAAN, University of Alabama at Birmingham.

Objectives

- Explain the experience and tasks undertaken by family caregivers of patients with advanced heart failure
- Summarize results and implications of the ENABLE CHF-PC trial for family caregivers.

Importance. Family caregivers (CGs) provide high levels of care to persons with advanced heart failure and are at high risk for distress and poor quality of life (QoL).

Objective(s). Determine the effect of a nurse-led palliative care telehealth intervention (ENABLE CHF-PC) on advanced heart failure CGs QoL and mood over 16 weeks.

Method(s). Intervention versus usual care single-blind randomized controlled trial (August 2016-October 2018; ClinicalTrials.gov: NCT02505425). Family caregivers of patients with NYHA Class III/IV heart failure were recruited from outpatient heart failure clinics at a large academic tertiary care medical center and a Veterans Affairs Medical Center. Intervention-group caregivers received four weekly psychosocial and problem-solving support telephonic sessions facilitated by a trained nurse coach plus monthly follow-up for 48 weeks. The primary outcomes were QoL (Bakas Caregiving Outcomes Scale [BCOS]), mood (Hospital Anxiety and Depression Scale [HADS]), and burden (Montgomery-Borgatta Caregiver Burden scale [MBCB]) over 16 weeks.

Results. Of 159 CGs randomized to ENABLE CHF-PC (n=83) or usual care (n=76), mean age was 57.9, 85.4% were female, 51.9% were African American, and 65.2% were the patient's spouse/partner. Over 16 weeks, the mean BCOS score improved 0.7 points (SE=1.7) in the intervention arm and 1.1 points (SE=1.6) in the usual care arm (difference, -0.4; 95% CI, -5.1-4.3; d=-0.03). No relevant betweengroup differences were observed for HADS-anxiety (d=-0.02), HADS-depression (d=0.03), and the MBCB scale (d range: -0.18-0.0). *P*-values for all outcomes were >.05.

Conclusion(s). This 2-site randomized controlled trial of the ENABLE CHF-PC intervention for family caregivers of advanced heart failure patients, over half of whom were African-Americans and most of whom were not distressed at baseline, did not demonstrate clinically improved QoL, mood, or burden compared to usual care over 16 weeks.

Impact. Future interventions should target distressed family caregivers and assess effects on patient outcomes.

Empowering Patient Participation in Advance Care Planning Discussions: Audio Recordings of Primary Care Visits Among PREPARE Randomized Trial Participants (CS201B)



Jennifer Freytag, PhD, Baylor College of Medicine. Deborah Barnes, PhD, University of California, San Francisco. Ying Shi, PhD, University of California, San Francisco. Aiesha Volow, MPH, University of California, San Francisco. Janet Shim, PhD, University of California, San Francisco. Stewart Alexander, PhD, Purdue University. Rebecca Sudore, MD FAAHPM, University of California, San Francisco and San Francisco Veterans Affairs.

Objectives

- Describe key elements of the PREPARE intervention.
- Evaluate PREPARE's effect on active patient participation in ACP discussions.

Importance. A patient-directed, online program (prepareforyourcare.org — PREPARE) increases ACP documentation. However, whether PREPARE empowers diverse older adults to actively participate in primary care ACP discussions is unknown.

Objective(s). Compare the efficacy of PREPARE plus an easy-to-read advance directive (AD) versus an AD alone to increase active patient participation in ACP discussions and examine effects of participation on documentation.

Method(s). We included English- and Spanishspeaking primary care patients ages 55 and older with serious or chronic illness from a VA and public hospital. Patients were randomized to review PRE-PARE and an easy-to-read AD or AD alone prior to their visit. Visits were audio-recorded. The primary outcome was the number of active patient participation utterances about ACP (e.g., asking questions, stating preferences) measured by the validated Active Patient Participation Coding Scheme. We examined differences by study arm using mixed-effects negative binomial models. We assessed utterances as a mediator of PREPARE's effect on ACP documentation using adjusted logistic regression and the Baron and Kenny method. Models were adjusted for health literacy, prior care planning, and clinician.

Results. Among 393 participants, the mean (SD) age was 66 (8.1), 120 (30.5%) had limited health literacy, and 99 (25.2%) were Spanish speaking. PRE-PARE plus the AD resulted in 41% more active patient participation in ACP discussions compared with the AD alone (10.1 utterances [16.8] vs. 6.6 [13.4]; IRR, 1.41; 95% CI, 1.00-1.98). For every additional utterance, participants had 15% higher odds of ACP documentation, and active patient participation accounted for 16% of PREPARE's effect on documentation.

Conclusion(s). The PREPARE program and easy-to-read AD empowered patients to actively participate in ACP discussions during primary care visits more than the AD alone without additional clinician- or system-level interventions.

Impact. The PREPARE program's focus on patient communication training may mitigate barriers to

patient-provider ACP conversations in busy outpatient settings.

Effectiveness of Advance Care Planning Group Visits for Older Adults in Primary Care (CS201C)



Hillary Lum, MD PhD, University of Colorado. Rebecca Sudore, MD FAAHPM, University of California, San Francisco and San Francisco VA. Jean Kutner, MD MPH FAAHPM, University of Colorado School of Medicine.

Objectives

- Describe how group visits can support behavior change.
- List core components of a primary care-based advance care planning (ACP) group visit model.
- Compare the effectiveness of an ACP group visit intervention with mailed materials on ACP outcomes.

Importance. Group visits can support behavior change. In primary care, an advance care planning (ACP) group visit intervention may leverage group dynamics to increase ACP engagement.

Objective(s). This trial aims to test the effect of a novel group visits intervention, Engaging in Advance Care Planning Talks (ENACT), to improve ACP documentation and readiness in older adults.

Method(s). We conducted a patient-level randomized clinical trial of ENACT Group Visits compared to Mailed ACP materials in a geriatric clinic. Patients were at least 60 years old and did not have significant hearing or cognitive limitations. ENACT Group Visits are two 2-hour sessions with up to 12 patients, co-facilitated by a physician and social worker. ACP topics include preferences for future medical care, surrogate decision-makers, and ACP documents. Mailed ACP materials arm received the Conversation Starter Kit and a Medical Durable Power of Attorney form. Primary outcome was advance directives in the electronic health record (EHR) at 6 months. Secondary outcomes included decision-maker documentation and readiness to engage in ACP actions (validated ACP Engagement Survey, 4-items on a 5-pt scale).

Results. Participants were a mean of 77 years old, 60% female, and 79% white. At 6 months, 45% of Mailed arm participants had an advance directive in the EHR, whereas 71% of ENACT participants had an advance directive (26% higher). Similarly, 73% in the Mailed arm compared to 93% of ENACT participants had surrogate decision-maker documentation in the EHR (29% higher) (p<0.001, both). Participants in the ENACT arm reported higher readiness to engage in ACP compared to the Mailed arm (4.1 vs 4.5, p=0.05).